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Review

# Digital Interventions to Support Adolescents and Young Adults With Cancer: Systematic Review

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## Abstract

**Background:** The last decade has seen an increase in the number of digital health interventions designed to support adolescents and young adults (AYAs) with cancer.

**Objective:** The objective of this review was to identify, characterize, and fully assess the quality, feasibility, and efficacy of existing digital health interventions developed specifically for AYAs, aged between 13 and 39 years, living with or beyond a cancer diagnosis.

**Methods:** Searches were performed in PubMed, EMBASE, and Web of Science to identify digital health interventions designed specifically for AYA living with or beyond a cancer diagnosis. Data on the characteristics and outcomes of each intervention were synthesized.

**Results:** A total of 4731 intervention studies were identified through the searches; 38 interventions (43 research papers) met the inclusion criteria. Most (20/38, 53%) were website-based interventions. Most studies focused on symptom management and medication adherence (15, 39%), behavior change (15, 39%), self-care (8, 21%), and emotional health (7, 18%). Most digital health interventions included multiple automated and communicative functions such as enriched information environments, automated follow-up messages, and access to peer support. Where reported (20, 53% of studies), AYAs' subjective experience of using the digital platform was typically positive. The overall quality of the studies was found to be good (mean Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields scores >68%). Some studies reported feasibility outcomes (uptake, acceptability, and attrition) but were not sufficiently powered to comment on intervention effects.

**Conclusions:** Numerous digital interventions have been developed and designed to support young people living with and beyond a diagnosis of cancer. However, many of these interventions have yet to be deployed, implemented, and evaluated at scale.

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**KEYWORDS**

adolescent; neoplasms; telemedicine; systematic review; eHealth

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## Introduction

**Background**

Globally, it is estimated that approximately 1 million adolescents and young adults (AYAs) between the ages of 15 and 39 years

are diagnosed with cancer each year [1]. Continual advances in cancer therapies now mean that the overall 5-year cancer survival rate among AYAs has increased to more than 80% with survival among some cancer diagnoses (eg, Hodgkin lymphoma, melanoma, and thyroid carcinoma) now exceeding 90% [2].

However, young people who have been diagnosed with cancer often face a myriad of physical, emotional, and psychosocial challenges because of their diagnosis and treatments [3,4]. During treatment, young people often experience prolonged periods of hospitalization and a number of symptoms and side effects such as neutropenia, nausea, alopecia, mucositis, and neuropathy. Post treatment, in survivorship, there is substantial evidence that AYAs diagnosed with cancer are at increased risk of developing long-term health conditions and experience high levels of pain, fatigue, and poor quality of life throughout their life course [5-7]. These difficulties are challenging for AYAs living with and beyond a diagnosis of cancer to manage and are faced at a time when they, as young people, should be establishing independence and autonomy [8,9]. Continual efforts are, therefore, being made in cancer care, research, and policy to ensure AYAs diagnosed with cancer receive the specialist medical, emotional, and practical support they require both during and after their cancer treatment [4,10,11].

Electronic health (eHealth), mobile health (mHealth; interventions delivered using mobile devices), and digital health interventions apply modern computing and technology innovations in the context of health care provision (the encompassing term *digital health interventions* has been adopted for the purpose of this review) and have been proposed as strategies to support young people with cancer manage the challenges associated with their diagnosis and treatment [12-14]. This is significant for AYAs in the context of their *digital native* status; for this population, continued exposure to and integration of digital interventions is the norm [15]. In the context of cancer, digital health interventions have the potential to widen access to and reach of support available to young people with cancer, particularly those being treated as outpatients or receiving long-term follow-up care. Moreover, the delivery of self-directed interventions remotely through digital technology has the potential to ease pressures on face-to-face services and overcome typical geographical and time-related constraints faced by patients, issues particularly pertinent among young people living with and beyond a diagnosis of cancer [16,17].

As demonstrated within the narrative review by Devine et al [18], there now exists a diverse range of digital health interventions for young people with cancer, which contain a variety of elements and functions. This is positive and reflects AYAs' preferences for information resources and self-management tools relevant to their diagnosis and experiences of cancer to be made available in digital formats [19-21].

In the digital health context, previous reviews of digital interventions have focused on health behavior change and have identified a number of key components that influence intervention outcomes. Existing reviews of digital interventions targeting health behavior change suggest user involvement in intervention design, mode of delivery (eg, Web-based, mobile based, through an advisor, telephone, or e-mail), synergistic use of behavior change techniques, and usability (ie, how easy is the digital health intervention to use and engage with) heavily influence intervention outcomes [22,23]. In this review, assessing these same components and also the quality (ie, the engagement, functionality, aesthetics, and subjective appeal)

of interventions is progressive and allows the utility of digital health interventions for AYAs diagnosed with cancer to be more definitively established. Moreover, assessing factors, which influence the engagement and compliance of AYAs living with and beyond a diagnosis of cancer with digital health interventions provide important insights into the feasibility of delivering self-directed interventions to this population in digital formats [24,25]. Understanding which component features of digital health interventions are most acceptable to AYAs diagnosed with cancer and whether such components affect intervention outcomes is critical to the development and evaluation of further digital interventions for young people with cancer [26]. Such data can be used to inform the design, development, and implementation of high-quality effective digital health interventions designed for AYAs diagnosed with cancer.

## Objectives

The objective of this review was to identify, characterize, and fully assess the quality, feasibility, and efficacy of existing digital health interventions developed specifically for AYAs living with and beyond a diagnosis of cancer.

This review aims to address the following questions:

1. What types of digital health and technology intervention have been used to support AYAs diagnosed with cancer? What is their primary focus?
2. Have digital health interventions designed to support AYAs living with and beyond a cancer diagnosis been thoroughly developed and tested?
3. What is the uptake and reach of digital health interventions designed to support AYAs diagnosed with cancer?
4. Is there sufficient evidence to state digital health interventions are an effective means to support AYAs diagnosed with cancer?

## Methods

### Overview

The full protocol for this review has previously been published [27]. To summarize, a literature search for digital health and technology interventions developed specifically for or piloted among AYAs diagnosed with cancer was conducted. Digital health interventions for the purpose of this review encompassed any eHealth, mHealth, or digital health effort, which applied modern computing and communication methods. The review was carried out following the Preferred Reporting Items for Systematic Review and Meta-Analyses guidelines [28].

### Eligibility Criteria

Studies were eligible if they were written in English and published in a peer-reviewed journal and reported or described any existing digital health intervention designed specifically for young people, aged 13 to 39 years, diagnosed with cancer. In this review, digital health interventions include any eHealth, mHealth, or digital health effort, which applied modern computing and technology innovations in the context of health care provision. Participants of interest are those aged between 13 and 39 years, defined as teenagers, adolescents, or young

adults living with or beyond a cancer diagnosis, and this was inclusive of survivors of pediatric cancer who fell within the age bracket of interest.

Studies were excluded if they had insufficient detail on the target population or included an incomplete and vague description of the digital health intervention of interest. If a study reported on interventions developed for young people with comorbid conditions other than cancer or if young people with cancer were not the main focus of the study, then the study was excluded. Studies that focused on the use of digital health interventions by parents or survivors of cancer over the age of 40 years were excluded, as were studies where the mean age of the sample was over 39 years.

### Search Strategy

Bibliographic databases (PubMed, Web of Science, and EMBASE) were searched in August 2016 and again in October 2017 for articles written in English and published to date in peer-reviewed scientific journals. A combination of Medical Subject Heading terms and keywords was used. These are available in [Multimedia Appendix 1](#).

### Selection of Studies

GP and LM screened the titles and abstracts of all studies identified during the search using the predetermined eligibility criteria of any study. The interrater agreement between both authors on the eligibility was high (Cohen kappa >0.90), and any instances of disagreement were resolved through discussion.

### Data Extraction

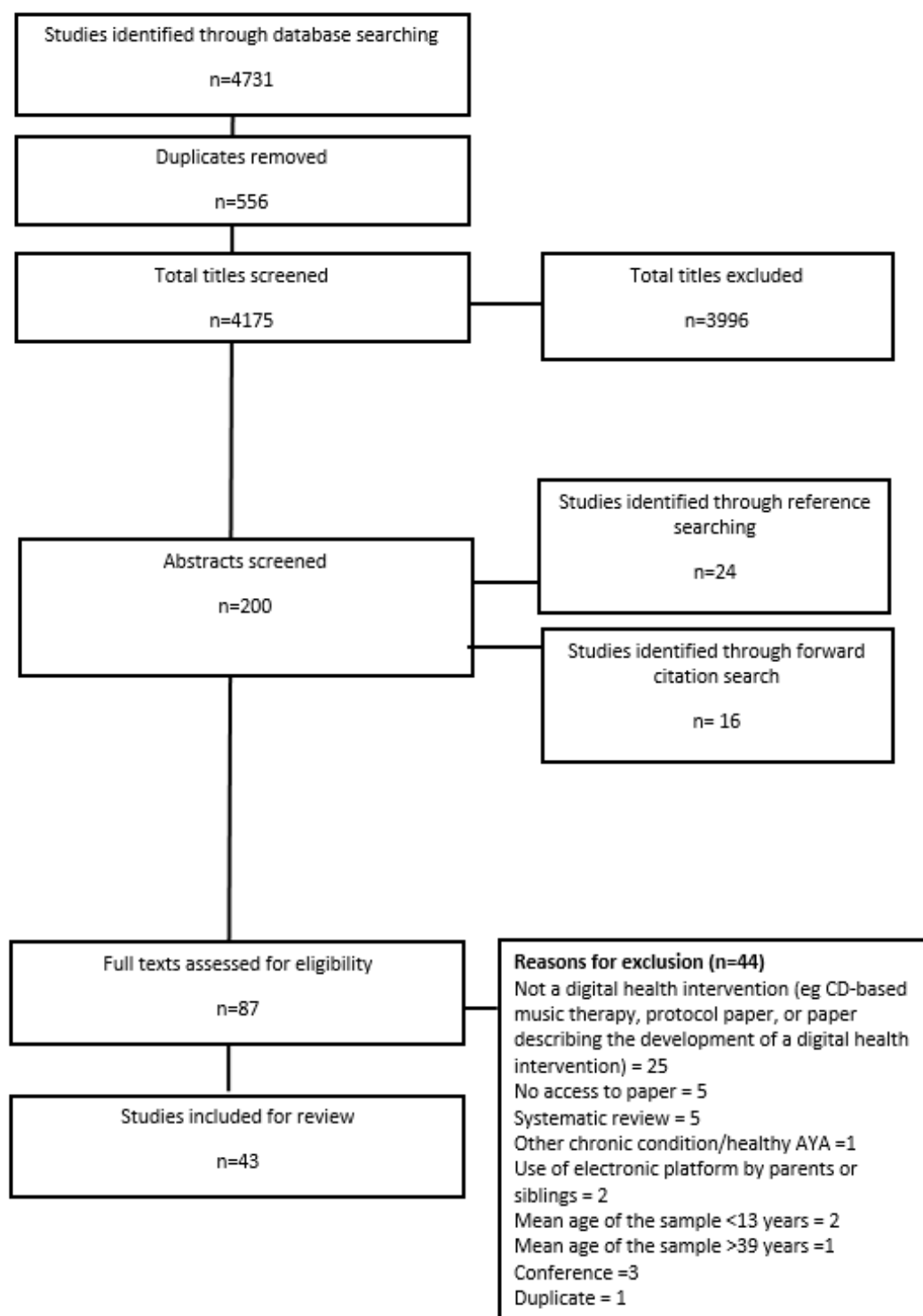
Data extraction was conducted by all authors using a template designed to collate details on each digital health intervention. Data included (1) study characteristics (country, design, sample size, target population, recruitment setting, aim, and methods), (2) platform development and design process (steering committee and patient and public involvement), (3) digital health intervention primary outcomes (mean change and effect size if

applicable), and (4) feasibility of delivering the intervention (acceptability, compliance, recruitment response, and retention to the intervention). The mode of digital health intervention delivery was coded into automated functions, communicative functions, and use of supplementary modes based on the coding scheme used by Webb et al [23]. An adapted version of the Mobile App Rating Scale (MARS) was used to group and classify reported engagement, functionality, aesthetics, information quality, and subjective quality of each digital health intervention [29]. Specifically, the theoretical background and strategies scale of the original MARS tool was used to classify the intervention features and theoretical design of each intervention. Alongside data extraction, methodological quality of the included studies was simultaneously assessed using the Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (QualSyst) tool [30]. QualSyst includes scoring systems for quantitative and qualitative studies; the maximum summary quality score for qualitative studies is 20 (10 items), and the maximum summary score for quantitative studies is 28 (14 items). Summary quality scores have been reported as percentages of maximum total scores, ranging from 0% to 100%. The higher the percentage score, the better methodological quality of the study, but no studies were excluded based on limited or reduced methodological quality. Following data extraction, included studies were rereviewed by GP, LM, and KM. Any discrepancies were resolved by discussion.

## Results

### Search Results

[Figure 1](#) outlines the search process. A total of 4731 studies were identified through the search. After screening the title of each paper, 195 were identified as potentially eligible, and the abstracts were screened. The full texts of 43 papers describing 38 studies were reviewed and subsequently selected for inclusion.

**Figure 1.** Preferred Reporting Items for Systematic Review and Meta-Analyses flow diagram. AYA: adolescents and young adult.

### Digital Health Interventions Characteristics

The characteristics of each of the 38 studies are summarized in [Multimedia Appendix 2](#). The included 43 papers reporting on these studies were published between 2002 and 2017. A range of study designs was reported. Of the included studies, 12 used a cross-sectional single-group design [31-42], 11 were randomized controlled trials (RCTs) [43-55], 7 were of single-group repeated measures design [56-65], 4 were of

qualitative design [66-69], 2 discussed the development of a digital health intervention [70,71], 1 used a mixed-methods approach [72], and 1 was a non-RCT [73]. Sample size ranged from 6 to 375, and age of participants ranged from 10 to 55 years (mean age <33 years). All included study participants were reported within the AYA age range (13-39 years) at the time of diagnosis. The duration of studies ranged from single-use interventions (eg, virtual reality [VR] glasses used during lumbar puncture) [73] to interventions available over long durations

(>6 months; eg, Partnership for Health-2, a Web-based smoking cessation intervention, which included a 15-month follow-up) [48].

### Methodological Quality of Reported Studies

[Multimedia Appendix 2](#) outlines the methodological quality of each quantitative and qualitative study. The QualSyst scores are reported as a percentage to allow a comparison to be drawn across study designs, as there are different assessment criteria for quantitative and qualitative studies [30]. Scores ranged from 35% to 100% and were distributed across this range, varying between and within study design. The mean score was 75% for RCTs (n=13) [43-55], 71% for the non-RCT study (n=1) [73], 70% for cross-sectional single-group studies (n=12) [31-42], 74% for repeated measures studies (n=10) [56-65], 62% for platform development studies (n=2) [70,71], 65% for the qualitative studies (n=4) [66-69], and 95% for the studies using a mixed-methods approach (n=1) [72]. Full details of the methodological quality of the papers can be found in [Multimedia Appendices 3](#) and [4](#).

### Patient and Public Involvement in Design

Of the 38 studies discussed across the 43 research papers included in this review, 14 were designed with young people's identifiable involvement in the process, and 8 had expert input or included a steering group in the design process.

### Target Behavior

A total of 15 interventions focused on symptom management and medication adherence [33,38,42,52,53,61-63,67,72,73], 8 on self-care [33,35,38,40,44,49,57,58,60], 15 on behavior change [35,37,40,44-47,50,54,64,65,70,71] (of which 6 addressed physical activity behavior [35,45-47,50]), 7 on negative emotions [31,40,44,49,57,58,74], 7 on physical health [33,35,44,46,47,50,63], 5 on anxiety or stress [41,43,49,50,71,73], 5 on goal setting [35,46,47,54,64], 4 on happiness and well-being [31,40,44,70], 4 on depression [31,40,44,49], 3 focused on relationships [40,66,71], 1 on education [40], and the focus of 1 intervention was to provide entertainment [40]. Across the included studies as a collective, there were multiple

occasions where the platform had more than 1 target behavior, as noted throughout this section.

### Intervention Features and Theoretical Design

The features used in the interventions were assessed using the MARS classification tool and are discussed in this section. There were 11 categories including an *other* category. Overall, 5 studies used assessment [42,45,62,63,73], 7 used feedback [32,40,42,45,54,65,66], 16 used information or educational strategies [31-33,37,43-47,51,62-65,68,69], 12 used monitoring or tracking [35,41,44,45,54,61-65,71,72], 8 used goal setting [31,35,40,44-47,54], 9 studies included advice or tips and skills building [44,45,51,56,60,62,65,69,71], and 1 used strengths-based strategies [64]. None of the studies included for review used mindfulness and meditation, relaxation, or gratitude strategies. Furthermore, 14 used strategies characterized as other [31,33,34,38,39,48-50,53,54,57,58,60,61,70]. Reported theories used to inform the intervention features included the theory of reasoned action [65], the Adolescent Resilience Model [49], the Hope Process Framework [39], the self-regulation model of health and illness [53], social cognitive theory [53], cognitive behavioral therapy [57,58], and the Symptom Management Theory [60].

### Digital Health Interventions for Adolescents and Young Adult Cancer Survivors: Component Features and Outcomes

[Multimedia Appendix 5](#) outlines the mode of delivery used for each digital health intervention, including details on automated and communicative function features within the platform. [Table 1](#) illustrates the different digital health interventions described in the 38 studies (43 papers) included in the review. As shown in [Table 1](#), there were 5 interventions in the other category; these included CD-ROM, computer program, digital storytelling, therapeutic music video, and e-mail. The following section summarizes the key outcome measures and findings from the studies categorized by platform and mode of delivery used. [Multimedia Appendix 5](#) gives more detailed insight into the automated functions, communicative functions, and supplementary modes of communication used in each study.

**Table 1.** Digital health interventions described in the studies which were included in the review (N=38).

Type of digital intervention	Studies, n (%)
Website	20 (53)
Mobile/tablet app	5 (13)
Video game	3 (8)
Wearable	2 (5)
Social media	1 (3)
Virtual reality	2 (5)
Other	5 (13)

### Websites

There were 20 studies where the digital intervention used was a website [31,36-39,41-45,48,56-58,64,66-69,71]. These studies had a variety of target behaviors and often had multiple outcome measures. Target behaviors included psychosocial and/or quality

of life [39,57,58,64], cancer knowledge and symptom management [31,38,43], physical activity and/or physical functioning [44,45,64], fertility [37,71], treatment and medication adherence [48], and co-design and development of a platform [71]. More than half the studies focused on the broader indicators of feasibility evaluations, acceptability,

usability, and intervention compliance, but measurement of these indicators varied from study to study with no consistency. Website designs varied from logs and diaries, game-like brain training exercises, written assignments where individual feedback was received from psychologists, weekly tips and tricks, and songwriting and video making exercises [31,36-39,41-45,48,56-58,64,66-69,71].

All studies focusing on physical activity and/or physical functioning saw an improvement [44,45,64]. The one study, using a website platform, that measured feasibility and acceptability of the intervention reported that 86% of participants would recommend the intervention, and 71% were satisfied with the intervention and the information available on the intervention website [45]. The more interactive websites, such as those including writing assignments [31,45], had a positive and stronger effect on psychosocial outcomes and quality of life than the more static interventions, where participants were provided with a treatment summary, contact details of health care professionals, or an electronic journal [43].

Hardy et al [56] reported a wide range of time spent on the website participating in the cognitive training intervention (mean=28.4 min over 12 weeks) with a mean of 11.4 training hours during the 12-week period. Seitz et al [57,58] reported that more than 80% of participants were satisfied with the psychotherapy intervention, and more than 80% indicated that the intervention, involving 10 written assignments, was relatively helpful in relieving the symptoms of posttraumatic stress disorder, anxiety, and depression. Furthermore, 90% of participants said they would recommend the website to a friend [57,58]. Moreover, 1 study described the development of 2 Web-based interventions using co-design [71]. A collaborative Patient Research Partner (PRP) approach was used to develop an internet portal focusing on fertility and sexuality and a self-help Web portal for young people with cancer. The PRPs provided feedback on content, system, and service quality. This led to the adaptation of the program, where the acceptability, feasibility, and functionality of the programs were examined [71]. In this case, users of both programs considered the content relevant and informative, and many expressed satisfaction with the website.

### **Mobile or Tablet App**

A total of 5 studies reported using a mobile phone or tablet app [32,33,40,59-63,67,72]. Of the 5 studies, 3 focused on symptom assessment and/or symptom management [32,59-61,72], whereas the other 2 studies focused more specifically on pain [33,62,63,67]. Apps developed to aid symptom assessment and symptom management tended to be positively reported [32,59-61,72], but definitive comparisons are difficult because of the different outcome measures used across these studies. For example, the Memorial Symptom Assessment Scale 10-18 was used in the evaluation of the app used by Rodgers et al [59,60]. Results from this evaluation demonstrated the prevalence of symptoms decreased over time ( $P=.006$ ), but there was no statistical difference over time in relation to symptom distress ( $P=.22$ ) [60]. In another study [32,72], participants completed the investigator-created Computerized Symptom Capture Tool on an iPad to report symptom experiences after

their first cycle of chemotherapy. Although acceptability data were not reported [72], it was noted that the app did identify a range of unique symptom clusters in these young adults. Most common symptom clusters were nausea, eating problems, and appetite problems, and the most frequently named priority symptom was nausea [32,72]. In their evaluation of a mobile electronic diary, called mOST, for AYAs with cancer to report daily symptoms of pain, nausea, vomiting, fatigue, and sleep, Baggot et al [61] reported an adherence rate of 97% over the 21 daily symptom reporting period. Encouragingly, high adherence rates were maintained throughout the evaluation period [61].

Mobile apps developed to assess and manage pain were also reported positively in 2 included studies. Pain Squad app by Stinson et al [33] was reported as being easy to use by most users (70.2%) and rated as quick to complete (91.7%). Evaluation of the second generation of this app, PainSquad+, by Jibb et al [62] also reported positive results with good initial adherence of their app at  $68.8\pm 38.1\%$ . Some decrease in adherence over time was noted by week 4 though at  $39.1\pm 38.1\%$ .

### **Video Games**

Overall, 3 studies reported using a video game as the platform for delivering the intervention [50,52,53,56]. The target behavior for each study differed: 1 focused on physical activity or physical functioning [50], another focused on cancer knowledge and treatment adherence [52,53], and another focused on memory, attention, and behavioral function [56].

The use of a video game to address these behaviors was reported as successful across all 3 studies respectively [50,52,53,56]. Cancer knowledge and treatment adherence improved in the Re-Mission video game intervention group [52,53], as they used the game as an educational tool, compared with the control group. Slight improvements in both physical activity and physical functioning measures over a 70-day intervention period were also noted for the intervention group [50]. In addition, the use of a game involving brain training exercises, such as Captain's Log, found improvements in working memory and attention problems [56]. This study by Hardy et al [56] was the only study using a video game where the feasibility and acceptability of the intervention were assessed. Hardy et al [56] reported compliance data, indicating that young people participated in a mean of 28.4 sessions and 11.4 training hours throughout the 12-week program.

### **Wearables**

Wearable physical activity trackers were used in 2 studies, and both studies had a main focus of improving physical activity of participants [35,54]. Of the 2 studies, 1 study simply used a consumer market device, a FitBit, to measure steps and encourage increased activity through monitoring [54], whereas the other study also used FitBits but supplemented this with a study-created private Facebook group that participants could use over the 10-week intervention period [54]. Both studies reported increases in physical activity following the intervention, and 1 reported on the intervention feasibility [54]. This was measured through FitBit wear time (71.5% of the available time) and participant engagement with the Facebook group, where



89.7% of participants joined the Facebook group, 92.3% of those saw at least one post, and 65.4% of those who joined commented on at least one post [54].

### **Social Media**

One study used the social media platform Facebook to deliver its intervention [46,47] where the focus was to increase physical activity in participants through educational posts with a focus on behavioral strategies for increasing activity [46,47]. Participants within this study also had access to a separate website with a goal setting and physical activity monitoring (diary) tool. Following the intervention, there was an increase in physical activity of 67 min/week in the intervention group and a significant loss in weight (-2.1 kg,  $P=0.004$ ).

### **Virtual Reality**

Two studies used VR glasses as the platform to deliver their interventions [70,73]. Of these 2 studies, 1 focused on pain during a lumbar puncture and evaluation of the intervention [73], whereas the other focused on the development of a VR counseling system [70]. Although not significant, pain scores were lower in the VR group compared with the control group, and 77% of users noted that the VR glasses and headphones helped to distract them during the lumbar puncture [73]. Because of poor recruitment, authors in the other study were unable to test and evaluate the VR counseling system they designed [70].

### **Other Intervention Types**

As shown in Table 1, there were 5 interventions in the other category: CD-ROM, computer program, digital storytelling, therapeutic music video, and e-mail [34,49,51,55,66,64]. The focus of these studies included building resilience [49], symptom management [49,55], cognitive function [34], education [51], social therapy [66], and health-promoting behaviors [64]. All studies were concluded feasible and acceptable to young people with cancer, with the majority reporting good uptake and engagement from participants.

### **Young Peoples' Subjective Experience of Using Digital Health Interventions**

A total of 20 studies reported young people's subjective experience of using the digital health intervention [38,39,43,45,48,50-52,54-58,61-63,66,67,69,72]. Subjective experience was typically measured as user satisfaction or appeal of the contents of the intervention. Within 11 studies, participants reported that they would either use the intervention again or would recommend it to a friend [38,39,48,51,52,55,57,58,61,62,65,67]. Very few studies reported participant's feedback on areas for improvement or recommendations for further platform developments. Of the studies that reported feedback, it was generally that the platform had technical problems, the visual design was too simple, or that the digital platform for communicating with other young people with cancer did not replace personal connection [66]. There was no clear pattern between intervention characteristics (delivery mode and focus of functional components) and engagement or adherence. Reasons for poor engagement or noncompliance were typically either not reported or attributed to recurrent illness [63,50]. Within 1 website-based study [69], incentives were introduced to improve compliance. Some studies

reported differences between the engagement and use of different features: for example, Rabin et al [45] reported that participants viewed pages on physical activity logging pages more often than physical activity tip pages of the intervention website (11.38 days vs 0.5 days). Similarly, Mendoza et al reported differences between participants' frequency of viewing, commenting, and liking Facebook posts within their intervention (92.3% vs 65.4% vs 50%, respectively).

### **Effect Sizes**

Only 7 of the 43 articles reviewed provided effect size within the original manuscript. Because of the heterogeneity in outcomes and differences in the characteristics of the intervention, it is not possible to make comparisons between the studies. A table summarizing the relevant data is available on request.

### **Reach**

The studies included in this review did not specifically report intervention uptake and reach. The total sample size of all studies gives some indication as to the number of people the interventions reached as a whole and the breakdown of where studies were conducted provides some guidance as to the characteristics of those participants. There was a total sample size of 1935 participants across the 38 studies. The majority ( $n=23$ ) of the digital health interventions were designed in the United States [31,32,34,35,39-47,49,51,54,56,59-61,64-66,68,73], 3 were designed in Canada [33,62,63,67], 2 in the Netherlands [36,38], 2 in Sweden [37,71], 2 reported multiple sites across different countries [48,52,53], and the country was not reported for 6 studies [50,55,57,58,69,70,72,75].

## **Discussion**

### **Principal Findings**

In this review, we have focused our attention on digital health interventions for AYAs diagnosed with cancer. We are not alone in our interest in considering digital health-driven interventions for AYA populations at this specific illness foci level [18] or indeed other relevant areas such as mental health [19], complex health care needs [75], and lifestyle behavior interventions for survivors of child and young adulthood cancer [13]. A recent narrative review of digital health interventions targeting AYA cancer survivors demonstrated the range of digital modalities used to support young people with cancer [18]. Our review has moved beyond the review of Devine et al [18] by not only identifying specific interventions but also drawing out components that contribute to appropriate digital interventions for our target population (AYA diagnosed with cancer). Our use of the Mode of Delivery [23] and MARS criterion [29], respectively, has allowed our synthesis to identify key components that may influence successful uptake of digital interventions to support this population in the future.

As stated in the Introduction section, we posed 4 key questions in this review. We have revisited these questions to frame our discussion.

### **What Types of Digital Health and Technology Intervention Have Been Used to Support Adolescents**

### ***and Young Adults Diagnosed With Cancer? What Is Their Primary Focus?***

We considered the mode of delivery (how the intervention was delivered to recipients) in the included studies and identified that websites were the most often used technology. Website designs and functionalities varied across this most prominent mode of delivery from simple logs and diaries to more interactive communications. Of note, given the review's inclusion timeline of 1970 to 2017 and the associated developments in the digital landscape in this time, it was observed that only 5 studies used mobile phone or tablet apps, and just 2 studies used wearable technologies as the mode of delivery for their associated interventions. We know that digital health interventions are rising in prominence and are helping to expand, assist, and enhance human activities within the context of health care [76]; therefore, whether this balance shifts in the future as even newer digital health innovations are developed remains to be seen.

The growth of the digital environment and associated digital health technologies are known as *disruptive innovations* [77] because they can lead to diverse, but improved, health outcomes [74]. The focus in some of the included studies in this review on improved health outcomes may explain why the observed target behaviors of the included digital interventions predominately focused on measurable outcomes related to symptom management and medication adherence, self-care, behavior change, and reducing negative emotions.

### ***Have Digital Health Interventions Designed to Support Adolescents and Young Adults Living With and Beyond a Cancer Diagnosis Been Thoroughly Developed and Tested?***

Studies included in this review were a mixture of randomized controlled trials, small-scale pilot studies, or qualitative explorations, which considered the feasibility and efficacy of digital health interventions developed specifically for AYAs living with or beyond a cancer diagnosis.

Our review illustrated that a range of digital health interventions has been developed for AYAs diagnosed with cancer, but few have actually progressed beyond small-scale piloting. This scalability restriction includes the website-based interventions, which may actually have the potential for wider dissemination than interventions that are hardware dependent for deployment. Moreover, even fewer appear ready for wide-scale implementation in routine care provision to help meet AYAs holistic and supportive care needs.

We did not extract information explicitly relating to any cost-effectiveness evaluations of the included interventions, but we did note during our synthesis that it was rare for a context such as this to feature prominently within any of the included articles. Similarly, it was challenging at times to identify explicit examples of interventions being scaled up and embedded within routine supportive care practices for AYAs with cancer.

Other reviews of digital health technologies have noted that engagement of end users in co-design activities throughout the innovation and development pathway for digital health

technologies is variable but essential to ensure long-term use and engagement with developed products [75]. In this review, we noted the involvement of young people in the design and development of the digital health intervention in less than half the studies reviewed. Although less than half of the studies reported on AYAs' subjective experiences of using the intervention, those that did, reported positive experiences.

### ***What Is the Uptake and Reach of Digital Health Interventions Designed to Support AYAs Diagnosed With Cancer?***

AYAs are typically referred to as digital natives: their continued exposure to and integration in a digital and electronic world is the norm [15]. Digital health care resources are increasingly desirable, and it is a commonplace for digital natives to be responsive to the use of digital technologies to manage their health care needs [21,78]. We found evidence to further support this position in our review for reasons that are threefold. First, we noted a total recruited sample size of 1935 AYAs across the 38 different interventions assessed within this review. Collectively, this provides a strong indication that there is positive traction for the uptake and reach of digital health interventions for AYAs diagnosed with cancer. Second, acceptability ratings of the digital interventions were reported in 58% of the included papers and were generally high. Finally, compliance rates, as reported in 61% of included papers, tended to be good and often sustained.

We observed across the 38 included studies that 18 interventions were primarily focused on supporting AYAs during active cancer treatment, and 20 were designed more explicitly for use across the long-term survivorship period. This further supports the notion that there is a role for digital health interventions to support AYAs with cancer at all stages of their cancer experience. Previous surveys with AYAs with cancer have identified preferences for digital tools to support experiences from diagnosis onward, including treatment and survivorship [21]. Other work has also highlighted the desire of young adult survivors of cancer of the introduction of digital tools to support self-management behaviors [16].

We are cognizant, however, of the context in which much of this work has been conducted. We noted that the majority of the evidence in this review has been drawn from work originating in the United States (61% of the included papers); therefore, there may be some bias in terms of uptake and reach in this regard.

The expanse now of what may be considered a digital health intervention meant the inclusion criteria in this review was purposely broad to capture a range of digital health interventions designed specifically for AYAs with cancer.

### ***Is There Sufficient Evidence to State Digital Health Interventions Are an Effective Means to Support Adolescents and Young Adults Diagnosed With Cancer?***

This systematic review highlighted that although there is a large quantity of good quality evidence in the field, drawing conclusive statements about the use of technology is difficult, given the heterogeneity of studies conducted. Our decision to

appraise the quality of included studies proved useful, as the overall quality of included studies was found to be good as they had a mean QualSyst score of greater than 68%. Some studies were methodologically noncomparable (eg, qualitative acceptability studies vs RCT trials), but generally, included studies were of good quality. Because of the heterogeneity between studies and descriptive reporting included within most, it was not possible to make conclusive statements about which delivery mode or intervention feature has the largest impact on outcome, engagement, or adherence.

We must be mindful of the different health care models and service provision contexts across the countries in which the studies were conducted (United States, Canada, the Netherlands, Sweden, and the United Kingdom), and associated evidence generated. The variability of these health care models (public, private, and insurance-based models of health care) should be considered too when interpreting the findings from this review. Consideration must also be given to the ethical and clinical challenges of using digital technology within AYA cancer services, as overarching principles of care and obligations to safeguard do not change [79]. This is particularly pertinent in instances where physical or psychosocial risks are captured or identified within the digital intervention, and there is a need for intervention or additional support to be provided to the patient [80]. Similarly, the extent to which digital resources are age-appropriate and tailored to the health literacy needs of AYA cancer patients should be addressed.

In addition, although our review has demonstrated digital interventions do provide opportunities to support AYAs diagnosed with cancer, it is challenging at this stage to definitively state which specific platform health care professionals should adopt or recommend to AYAs they care for. Many interventions have yet to be deployed and implemented at scale. If this status quo remains, care provision will not evolve in tandem with technological developments and the growing digital health landscape in which global health services are increasingly situated. This is a challenge to be addressed by colleagues and peers working across both clinical and research AYA cancer fields. Efforts should focus on international collaborations to drive forward interventions on the cusp of upscaling and capable of providing gold standard evidence. Given the relatively small number of AYA cancer survivors globally, efforts to replicate studies using the same outcome measures in other countries should be made. Testing the impact and effect of digital health interventions for AYA cancer survivors beyond traditional RCT models is increasingly necessary to reflect the pace at which developments are occurring and the agile nature of digital technology. Innovation in the context of methodologies alongside innovation in the context of interventions (point of diagnosis, during treatment, and posttreatment) is going to be essential to best inform digital health implementation within routine care provision in the future.

### Strengths and Limitations

Our review has a number of strengths and limitations. We focused our review attentions on digital health interventions designed specifically for AYAs with cancer, and we used broad

age inclusion criteria in this regard, from 13 to 39 years. Although this may seem too broad to some, to ensure our review was inclusive as possible and of international significance and relevance, we drew on a range of relevant cancer policy context definitions of AYA [81]. There were some challenges encountered with this, particularly in terms of papers, which included the older spectrum of our target participants (>26 years). Given the international variations in definitions of AYAs with cancer, papers that included these upper ranges of AYA had to be excluded from the review, as it was not possible for us to readily identify data specifically focused on the population up to 39 years, particularly if the intervention had been developed in the context of a wider adult cancer population. Although we searched a range of databases, these were limited to the most common, and we limited our searches to peer-reviewed articles, thereby excluding gray literature. Also, as we limited our searches to papers published in English language only, this may be considered a limitation by some.

To meet our review objective of identifying, characterizing, and fully assessing the quality, feasibility, and efficacy of existing digital health interventions developed specifically for AYAs living with or beyond a cancer diagnosis, our data extraction process was long and detailed. In addition to our study characteristic extractions, we also used 2 specific rating tools relevant for a focus on digital interventions: Mode of Delivery [23] and MARS [29]. Overall, the Mode of Delivery proved a useful and straightforward tool to use, but we encountered some difficulties with the MARS tool. It became increasingly apparent that for the impact of this tool to be realized, one requires full and ready access to the particular app being reviewed and rated. As we were reviewing the published evidence of digital interventions (and not just digital interventions that were publicly and commercially available on app stores such as others who have used the MARS tool in previous reviews [82,83]), we had only narrative descriptions of the apps or interventions to go by in the papers and on occasion, supplemented with screenshots of aspects of the intervention. We were therefore limited to only reporting selected, but still useful, thematic information. Additional items of the MARS were answered if published detail allowed. Although we persevered with this extraction tool throughout our review process, we were unable to draw insightful conclusions because of omission of detail on user interactivity with the digital health intervention, functional performance, ease of use, and graphic design features within manuscripts. We reflect on this as a limitation of the MARS tool itself as much as our review.

### Conclusions

This review is positive in that it has highlighted that multiple digital health interventions do now exist to support AYAs diagnosed with cancer. The everyday technology-driven environment in which we now live has expedited the development pathway for digital interventions in health care contexts. However, within our review, it was rare to identify innovations that are ready to be or have already been deployed and implemented at scale. We find ourselves with a case of digital health *pilotitis* and efforts now need to shift; therefore, the most robust evidence-based innovations are routinely implemented in clinical practice. There is insufficient evidence

to state conclusively which form of digital intervention is the best approach to support young people with cancer. Currently, it is challenging to provide clinicians working directly with AYAs with cancer with definitive options for valid, reliable, and robustly evaluated digital tools and interventions to use as part of their health care services. Therefore, to really establish

the impact of digital interventions on health-related outcomes of AYAs with cancer and the economic value of implementing digital interventions on service design and service delivery, future endeavors should prioritize upscaled and robust outcome-driven interventions and associated evaluations.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Medical subject heading terms.

[[PDF File \(Adobe PDF File\), 27KB - cancer\\_v5i2e12071\\_app1.pdf](#) ]

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## Multimedia Appendix 2

A summary of research studies included in the review.

[[PDF File \(Adobe PDF File\), 133KB - cancer\\_v5i2e12071\\_app2.pdf](#) ]

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## Multimedia Appendix 3

QualSyst Scores for Qualitative Papers.

[[PDF File \(Adobe PDF File\), 40KB - cancer\\_v5i2e12071\\_app3.pdf](#) ]

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## Multimedia Appendix 4

QualSyst Scores for Quantitative Papers.

[[PDF File \(Adobe PDF File\), 84KB - cancer\\_v5i2e12071\\_app4.pdf](#) ]

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## Multimedia Appendix 5

Mode of delivery.

[[PDF File \(Adobe PDF File\), 134KB - cancer\\_v5i2e12071\\_app5.pdf](#) ]

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## Abbreviations

**AYAs:** adolescents and young adults

**eHealth:** electronic health

**MARS:** Mobile App Rating Scale

**mHealth:** mobile health

**PRP:** Patient Research Partner

**QualSyst:** Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Field

**RCT:** randomized controlled trial



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Original Paper

# Developing Machine Learning Algorithms for the Prediction of Early Death in Elderly Cancer Patients: Usability Study

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## Abstract

**Background:** The importance of classifying cancer patients into high- or low-risk groups has led many research teams, from the biomedical and bioinformatics fields, to study the application of machine learning (ML) algorithms. The International Society of Geriatric Oncology recommends the use of the comprehensive geriatric assessment (CGA), a multidisciplinary tool to evaluate health domains, for the follow-up of elderly cancer patients. However, no applications of ML have been proposed using CGA to classify elderly cancer patients.

**Objective:** The aim of this study was to propose and develop predictive models, using ML and CGA, to estimate the risk of early death in elderly cancer patients.

**Methods:** The ability of ML algorithms to predict early mortality in a cohort involving 608 elderly cancer patients was evaluated. The CGA was conducted during admission by a multidisciplinary team and included the following questionnaires: mini-mental state examination (MMSE), geriatric depression scale-short form, international physical activity questionnaire-short form, timed up and go, Katz index of independence in activities of daily living, Charlson comorbidity index, Karnofsky performance scale (KPS), polypharmacy, and mini nutritional assessment-short form (MNA-SF). The 10-fold cross-validation algorithm was used to evaluate all possible combinations of these questionnaires to estimate the risk of early death, considered when occurring within 6 months of diagnosis, in a variety of ML classifiers, including Naive Bayes (NB), decision tree algorithm J48 (J48), and multilayer perceptron (MLP). On each fold of evaluation, tiebreaking is handled by choosing the smallest set of questionnaires.

**Results:** It was possible to select CGA questionnaire subsets with high predictive capacity for early death, which were either statistically similar (NB) or higher (J48 and MLP) when compared with the use of all questionnaires investigated. These results show that CGA questionnaire selection can improve accuracy rates and decrease the time spent to evaluate elderly cancer patients.

**Conclusions:** A simplified predictive model aiming to estimate the risk of early death in elderly cancer patients is proposed herein, minimally composed by the MNA-SF and KPS. We strongly recommend that these questionnaires be incorporated into regular geriatric assessment of older patients with cancer.

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**KEYWORDS**

geriatric assessment; aged; machine learning; medical oncology; death

## Introduction

### Background

Aging is a complex and personal, cumulative, and irreversible phenomenon that goes well beyond chronological age [1]. It involves several biological events associated with a great variety of molecular and cellular damage, leading to the gradual loss of physiological and immunological reserves and a greater risk for neoplasia-related death [1,2]. Assuming that the elderly population is heterogeneous, this population must be considered not only concerning their chronological age. Thus, an objective analysis of their living conditions as well as aspects related to oncological disease and its therapy is also required [3].

The International Society of Geriatric Oncology has recommended the use of the Comprehensive Geriatric Assessment (CGA) for the evaluation and follow-up of elderly cancer patients [4]. The CGA is a multidisciplinary tool that uses validated instruments to evaluate several elderly health condition domains, such as functional, cognitive, psychological, social, clinical, and nutritional aspects, as well as comorbidities and the use of medication, among others [5,6]. It is also strongly recommended by the geriatrics and gerontology fields in general because it is, in a complex and heterogeneous context, an objective, measurable, and reproducible form of evaluation, adding possibilities to standard clinical laboratory evaluations [7,8]. However, there is no consensus about what and how many instruments should be used. Employing CGA in practice, however, has become a huge challenge, and owing to its complexity and time spent in its application, it is often underutilized by oncologists and not judged as a completely satisfactory solution in practice, which has served as a stimulus for the construction of simpler tools that have the power to predict outcomes and guide clinical decisions [5,9].

The accurate prediction of a disease outcome is one of the most interesting and challenging tasks for physicians. As a result, a growing trend was noted in the studies published during the past years that applied machine learning (ML) algorithms for modeling cancer survival. This type of algorithms can discover and identify patterns and relationships between them, from

complex databases, while they are able to effectively predict future outcomes of a cancer type [10]. On the basis of the study by Kourou et al [11], the accuracy of cancer prediction outcome has significantly improved by 15% to 20% in the previous years, with the application of ML techniques.

A study combining data from 4 cohorts involving the elderly, 1 including elderly people with neoplasms, proposed to explore the performance of various ML classifiers (Naive Bayes [NB], k-nearest neighbors, artificial neural networks, random forest, and logistic regression) regarding death prediction in 6 months [12]. Another study used ML to predict mortality of patients in 3 to 12 months and to identify patients who could benefit from palliative care [13]. However, no ML application has been proposed using CGA to classify elderly cancer patients.

### Objectives

Thus, the primary aim of this study was to propose and develop predictive models, using ML and CGA, to estimate the risk of early death in elderly cancer patients. The secondary aims were to optimize the CGA through the selection of the most appropriate instruments.

## Methods

### Comprehensive Geriatric Assessment

The ability of ML techniques to predict early mortality in a heterogeneous cohort was tested in 608 elderly cancer patients (aged over 60 years), admitted to the oncogeriatrics sector of the Instituto de Medicina Integral Prof. Fernando Figueira - IMIP, from January 2015 to July 2016. The IMIP is a teaching hospital and cancer center located in Recife, Pernambuco, Brazil. On admission to the cohort database, the patients were evaluated by CGA questionnaires presented in Table 1. The questionnaires were collected by a multiprofessional team, comprising a clinical oncologist, a geriatrician, a physiotherapist, a physical educator, a speech therapist, an occupational therapist, and a nutritionist. The project was approved by the IMIP Ethics Committee on Human Research on June 30, 2016, under number 58298316.5.0000.5201.

**Table 1.** Questionnaires/features to evaluate elderly health condition domains in Comprehensive Geriatric Assessment.

Questionnaire/feature	Perspective	Range/cutoff
Charlson comorbidity index [14]	A prospective method for classifying comorbid conditions that might alter the risk of mortality	0 to 37 points, with an increase of up to 5 points per age range
Geriatric depression scale-short form [15]	A self-report measure of depression in older adults. Users respond in a yes/no format	score 0 to ≤5 is normal; score >5 is depression
International physical activity questionnaire-short form [16]	A set of questionnaires to obtain international comparative data on physical activity	0 is sedentary, 1 is insufficiently active, 2 is active, 3 is active, and 4 is very active
Karnofsky performance scale [17]	Used to quantify patients' general well-being and activities of daily life	0 to 100, the lower the score, the worse the survival for most serious illnesses
Katz index of independence in activities of daily living [18]	Was developed to study results of treatment and prognosis in the elderly and chronically ill. Grades of the index summarize overall performance in bathing, dressing, going to toilet, transferring, continence, and feeding	0 to 6, high score means patient is independent and low score means patient is very dependent
Mini-mental state examination [19]	A method for grading the cognitive state of patients for the clinician	0 to 30, the lower the score rate, the worse the cognitive impairment
Mini nutritional assessment-short form [20]	A screening tool used to identify older adults who are malnourished or at risk of malnutrition. Comprises 6 questions on food intake, weight loss, mobility, psychological stress or acute disease, presence of dementia or depression, and body mass index	0 to 14, scores of 12-14 are considered normal nutritional status; 8-11 indicate at risk of malnutrition; and 0-7 indicate malnutrition
Polypharmacy [21]	Refers to the regular use of a greater number of medicines (5 or more drugs)	0 is no; 1 is yes
Timed up and go [22]	The patient is observed and timed while he rises from an arm chair, walks 3 m, turns, walks back, and sits down again	0 is low risk of falling (less than 20 seconds), 1 is average risk of falling (20-29 seconds), and 2 is high risk of falling (30 seconds or more)

## Preprocess of Database

The first step was to remove patients presenting redundancies and/or incomplete questionnaires/features. A total of 543 patients remained after that. Data normalization technique for equalizing the range of features, usually employed in the database before feature selection and learning phase, is of important concern in pattern recognition and computer-aided diagnosis [23]. The most common normalization method used during data transformation is the min-max (where the features are mapped into a predefined range, varying from 0 or -1 to 1). The main advantage of min-max normalization is that it preserves the relationships among the original data values [24]. In this work, all features were normalized in a (0,1) interval, calculated as in equation, where  $v'$  is the value normalized,  $v$  is the original value,  $v_{min}$  is the minimum value of corresponding feature, and  $v_{max}$  is the maximum value of corresponding feature:

$$v' = (v - v_{min}) / (v_{max} - v_{min}).$$

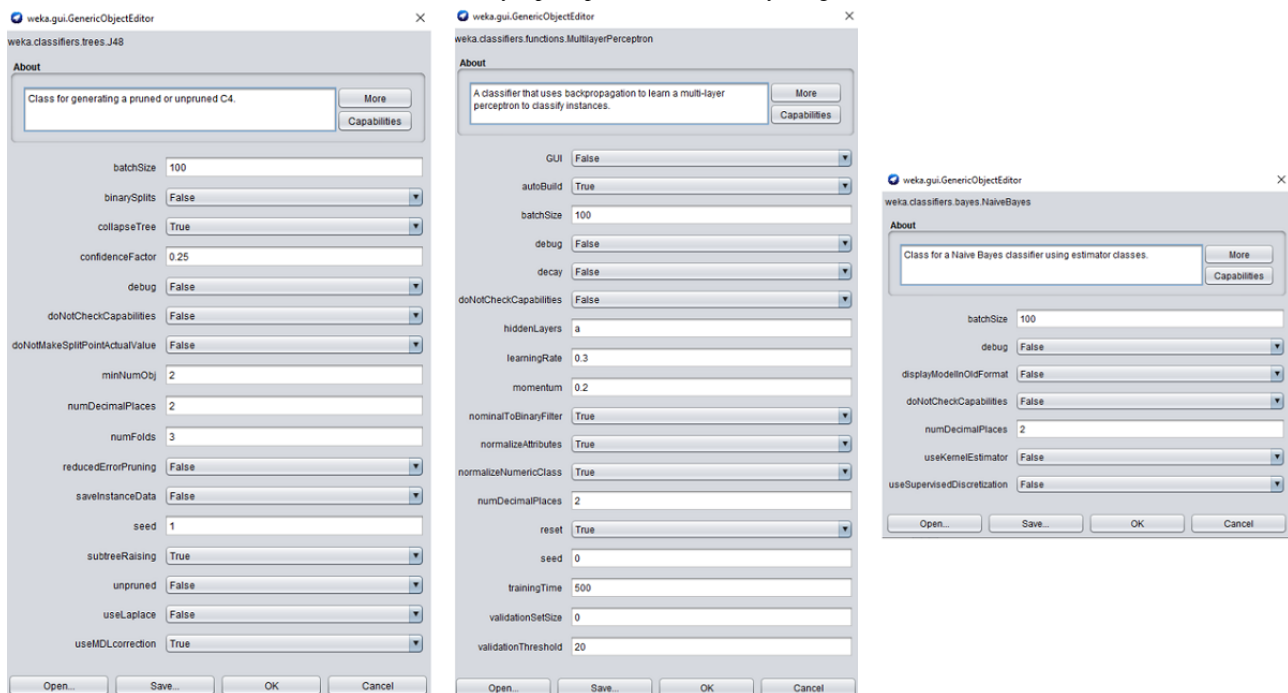
## Predictive Models

Predictive modeling is the general concept of building a model that can make predictions. Typically, such a model includes an ML algorithm that learns certain properties from a database to

make those predictions. We have presented below a brief summary of the commonly used supervised learning algorithms:

- Decision tree J48 (J48) [25]: They are tree-like graphs, where the nodes in the graph test certain conditions on a set of features and the branches split the decision toward the leaf nodes. The leaves represent the lowest level in the graph and determine the class labels.
- Multilayer perceptron (MLP) [26]: They are graph-like classifiers that mimic the structure of a human or animal brain where the interconnected nodes represent the neurons.
- Naïve Bayes (NB) [27]: They are based on a statistical model (ie, Bayes theorem, calculating posterior probabilities based on the prior probability and the so-called likelihood).

The purpose of this work was not to introduce the highest accuracy prediction model. The goal was to designate the most relevant questionnaires to evaluate elderly health condition domains in CGA. Therefore, in the experiments, we always used the same configuration with the default parameter values in Weka (Waikato Environment of Knowledge Analysis) from The University of Waikato, version 3.8.3. The advantage of using default parameters is that it does not introduce optimistic bias by tuning the parameter to maximize performance on the test data. Figure 1 shows more details about the values used in each predictive model.

**Figure 1.** Parameters used in Decision Tree (J48), Multilayer perceptron, and Naive Bayes algorithms.

## K-Fold Cross-Validation

Cross-validation (CV) [28] is one of the most widely used methods to assess the generalizability of predictive models [29] and is subject to ongoing active research [30]. K-fold CV comprises dividing the database into K parts (folds) of equal sizes. For this study, a 10-fold CV is used, and each part is held out in turn and the predictive model (J48, MLP, or NB) is trained on the remaining nine-tenths; then, its error rate is calculated on the holdout set. Thus, the learning procedure is executed a total of K times on different training sets (each of which have much in common). Finally, the K error estimates are averaged to yield an overall error estimate. In this work, the folds are made by preserving the percentage of samples for each class.

## Imbalanced Learn

The learning procedure and the subsequent prediction of predictive models can be affected by the problem of imbalanced database [31]. The balancing issue corresponds to the difference in the number of samples in the different classes. The resulting database presented 92 deaths within 6 months of admission to the service and 451 patients alive at the end of that period. All deaths were attributed to cancer (treatment complications or disease progression). With a greater imbalanced ratio, the decision function favors the class with the largest number of samples, usually referred as the majority class. The way to fight this issue was to generate new training sets on 10-fold CV by random sampling so that the proportion between classes remained at one-to-one.

## Metrics

The area under receiver operating characteristics curve, or simply area under curve (AUC), has recently been proposed as

an alternative single-number measure for evaluating the generalization of learning algorithms [32]. This measure is far better than classification accuracies when the 2 classes are unbalanced and the cost of misclassification is unspecified [33]. An area of 1.0 represents a model that made all predictions perfectly, and an area of 0.5 represents a model as good as random. AUC can be broken down into sensitivity and specificity:

- Sensitivity is the true positive rate, and for this study, it is the percentage of patients with early death that are predicted correctly.
- Specificity is also called the true negative rate, for example, the percentage of patients without early death that are predicted correctly.

## Results

### Evaluating All Possible Combinations of Comprehensive Geriatric Assessment Questionnaires

Feature selection is an important and frequently used technique for dimension reduction by removing irrelevant and/or redundant information from the database to obtain an optimal feature subset. A 10-fold CV was used to evaluate all possible combinations of CGA questionnaires, presented in Table 2, to estimate the risk of early death in elderly cancer patients. Thus, in each fold, the combination of questionnaires with highest AUC is selected. The same folds are applied to all 511 combinations. Tiebreaking is handled by choosing the smallest set of questionnaires. The occurrence of questionnaires selected on the 10-fold CV, using predictive models, is presented in Table 2. In Figure 2, the flowchart of our methodology is shown.

**Table 2.** Occurrence of the Comprehensive Geriatric Assessment questionnaires in the 10-folds using decision tree (J48), multilayer perceptron, and Naive Bayes.

Model	Charlson co-morbidity Index	Geriatric depression scale-short form	International physical activity questionnaire-short form	Katz index of independence in activities of daily living	Karnofsky performance scale	Mini-mental state examination	Mini nutrition-al assessment-short form	Polypharmacy	Timed up and go
Decision tree	6	4	0	4	1	1	10	2	2
Multilayer perceptron	0	0	0	0	10	1	10	0	0
Naive Bayes	9	6	6	0	10	10	10	2	0

**Figure 2.** Flowchart of methodology.

Variable	Control group (n=58)	Intervention group (n=60)
<b>Sociodemographic characteristics</b>		
Age (years), mean (SD)	39.7 (5.2)	38.4 (5.2)
Parity <sup>a</sup> , mean (SD)	3.8 (1.9)	4.3 (1.8)
<b>Marital Status, n (%)</b>		
Single	3 (5)	4 (7)
With a partner	55 (95)	56 (93)
<b>Education level, n (%)</b>		
None	11 (19)	1 (2)
Elementary school	1 (2)	11 (18)
Apprenticeship	33 (56)	3 (5)
High school	13 (22)	38 (63)
University	— <sup>e</sup>	7 (12)
<b>Employment status, n (%)</b>		
Employed	38 (65)	40 (67)
Farmer	2 (3)	4 (7)
Housewife	15 (26)	13 (22)
Other	3 (5)	3 (5)
<b>Clinical characteristics</b>		
<b>HPV<sup>b</sup> test result<sup>c</sup>, n (%)</b>		
Negative	41 (71)	36 (60)
HPV-16	—	2 (3)
HPV-18/45	4 (7)	3 (5)
Other hrHPV <sup>d</sup>	12 (21)	19 (32)

### Evaluating combinations of occurrences

Tables 3-5 show the sensibility, specificity, and AUC values expressed as mean (SD) on the 10-fold CV for the NB, J48, and MLP. The subsets of CGA questionnaires, presented in these tables, consider the occurrences of Table 2. The subset of questionnaires with occurrence  $\geq 0$ , for example, uses all set of CGA questionnaires, as it considers all occurrences greater than or equal to 0. The other subsets use the same logic and are

detailed in the footnotes under the tables. In each metric, according to the paired  $t$  test, the  $P$  value is calculated considering the subset of questionnaires with occurrence  $\geq 0$ . The experimental results demonstrate that the feature selection can discard questionnaires and finally find out subsets that reduce the dimensionality of data to make the predictive models more efficient and the results more accurate. Thus, a simplified predictive model aiming to estimate the risk of early death in elderly cancer patients is proposed herein, minimally composed

by the Mini Nutritional Assessment-Short Form (MNA-SF), and/or the Mini-Mental State Examination, accompanied or not by the Karnofsky performance scale (KPS)

**Table 3.** Metrics considering Comprehensive Geriatric Assessment questionnaire subsets on Naive Bayes classifier.

Metric	Subsets of questionnaires with occurrence						
	$\geq 0$ occurrences <sup>a</sup>		$\geq 6$ occurrences <sup>b</sup>		$\geq 9$ occurrences <sup>c</sup>		10 occurrences <sup>d</sup>
	Mean (SD)	Mean (SD)	<i>P</i> value	Mean (SD)	<i>P</i> value	Mean (SD)	<i>P</i> value
Sensibility	81.61 (4.62)	78.50 (6.3)	.02	80.28 (6.79)	.22	78.51 (5.00)	.003
Specificity	65.89 (14.72)	76.89 (12.48)	.002	71.45 (13.35)	.03	72.56 (12.31)	.01
AUC <sup>e</sup>	82.43 (6.35)	83.35 (6.9)	.16	83.31 (6.8)	.17	82.82 (6.78)	.37

<sup>a</sup> $\geq 0$  occurrences: All comprehensive geriatric assessments (Charlson comorbidity index, geriatric depression scale-short form, international physical activity questionnaire-short form, Katz index of independence in activities of daily living, Karnofsky performance scale, mini-mental state examination, mini nutritional assessment-short form, polypharmacy, and timed up and go).

<sup>b</sup> $\geq 6$  occurrences: Charlson comorbidity index, geriatric depression scale-short form, international physical activity questionnaire-short form, Karnofsky performance scale, mini-mental state examination, and mini nutritional assessment-short form.

<sup>c</sup> $\geq 9$  occurrences: Charlson comorbidity index, Karnofsky performance scale, mini-mental state examination, and mini nutritional assessment-short form.

<sup>d</sup>10 occurrences: Karnofsky performance scale, mini-mental state examination, and mini nutritional assessment-short form.

<sup>e</sup>AUC: area under curve.

**Table 4.** Metrics considering comprehensive geriatric assessment questionnaire subsets on decision tree (J48) classifier.

Metric	Subsets of questionnaires with occurrence						
	$\geq 0$ occurrences <sup>a</sup>		$\geq 4$ occurrences <sup>b</sup>		$\geq 6$ occurrences <sup>c</sup>		10 occurrences <sup>d</sup>
	Mean (SD)	Mean (SD)	<i>P</i> value	Mean (SD)	<i>P</i> value	Mean (SD)	<i>P</i> value
Sensibility	70.34 (16.79)	75.16 (6.38)	.13	69.80 (12.13)	.47	62.12 (7.25)	.04
Specificity	62.89 (15.11)	71.67 (16.77)	.07	75.78 (26.22)	.11	84.56 (13.09)	.001
AUC <sup>e</sup>	67.55 (10.27)	78.79 (8.41)	.003	78.08 (8.74)	.006	76.97 (10.12)	.02

<sup>a</sup> $\geq 0$  occurrences: all comprehensive geriatric assessments (Charlson comorbidity index, geriatric depression scale-short form, international physical activity questionnaire-short form, Katz index of independence in activities of daily living, Karnofsky performance scale, mini-mental state examination, mini nutritional assessment-short form, polypharmacy, and timed up and go).

<sup>b</sup> $\geq 4$  occurrences: Charlson comorbidity index, geriatric depression scale-short form, Katz index of independence in activities of daily living, and mini nutritional assessment-short form.

<sup>c</sup> $\geq 6$  occurrences: Charlson comorbidity index and mini nutritional assessment-short form.

<sup>d</sup>10 occurrences: mini nutritional assessment-short form.

<sup>e</sup>AUC: area under curve.

**Table 5.** Metrics considering comprehensive geriatric assessment questionnaires subsets on multilayer perceptron classifier.

Metric	Subsets of questionnaires with occurrence					
	$\geq 0$ occurrences <sup>a</sup>		$\geq 1$ occurrence <sup>b</sup>		10 occurrences <sup>c</sup>	
	Mean (SD)	Mean (SD)	<i>P</i> value	Mean (SD)	<i>P</i> value	
Sensibility	68.75 (8.34)	73.87 (9.68)	.03	77.41 (9.12)	.01	
Specificity	62.67 (17.84)	74.89 (9.37)	.03	72.45 (12.35)	.03	
AUC <sup>e</sup>	69.64 (9.83)	80.33 (6.86)	.005	82.33 (6.26)	.002	

<sup>a</sup> $\geq 0$  occurrences: all comprehensive geriatric assessments (Charlson comorbidity index, geriatric depression scale-short form, international physical activity questionnaire-short form, Katz index of independence in activities of daily living, Karnofsky performance scale, mini-mental state examination, mini nutritional assessment-short form, polypharmacy, and timed up and go).

<sup>b</sup> $\geq 1$  occurrence: Karnofsky performance scale, mini-mental state examination, and mini nutritional assessment-short form.

<sup>c</sup>10 occurrences: Karnofsky performance scale and mini nutritional assessment-short form.

<sup>e</sup>AUC: area under curve.



## Discussion

### Principal Findings

Results indicate that the MNA-SF has greater predictive power to estimate the risk of early death in elderly cancer patients as it was selected on the 10-folds. MNA-SF is a rapid test validated for screening for nutritional risk and malnutrition in the elderly population. The predictive value of MNA-SF for early death may be related to the fact that the 6 MNA-SF questions cover areas other than just nutrition, which are frequently included in the CGA, such as mobility, neuropsychological disorders, and self-reported health, in addition to nutrition aspects, including weight loss, reduced food intake, and body mass index. In fact, low MNA-SF may reveal the effects of advanced disease in the overall health of patients, which also affects cancer-related mortality. A Brazilian study showed that abnormal nutritional status was an independent factor associated with hospital death among older patients with various chronic diseases, including cancer [34]. A similar association was also demonstrated in elderly Asian cancer patients who would receive first-line chemotherapy [35]. Finally, a French multicenter study with 348 elderly cancer patients aged 70 years and above also found that low MNA scores were associated with increased risk of premature death [36].

The results also indicated that KPS questionnaire has proven itself a valuable tool to estimate the risk of early death in elderly cancer patients. In the past decades, various studies have demonstrated the prognostic value of the KPS not only primarily for various cancers [37-40] but also for other disease entities [41]. It can also be considered as a significant indicator of hospitalization and survival time, in addition to identifying risk

groups to assist in the orientation of patients to geriatric outpatients [42].

### Limitations

The efforts of this paper are a starting point. They provide solid evidences and some clinical recommendations. We proposed and developed simple ML models for the prediction of early death in elderly cancer patients. These models are accurate and precise and could be possibly used by clinicians to make proper treatment plans. However, additional research is needed to continue to strengthen the evidence base.

### Conclusions

The results showed that the MNA-SF and KPS have the highest predictive power to identify elderly patients at risk for early death. We strongly recommend that these questionnaires be incorporated into regular geriatric assessment of older patients with cancer.

The MNA-SF and the KPS requires only a few minutes to be completed. In addition, both can be easily managed by any member of the multidisciplinary team to help in the early identification of patients at risk, providing information that assists in the planning of interventions and improving the adherence to CGA in daily clinical oncology practice.

This study also has limitations that should be considered. This is a nonrandomized, single-center, exploratory study of a heterogeneous patient population similar to a real-life population of older patients with cancer. Conversely, some of its weaknesses could be considered the main strengths of the study: this is one of the few studies in Brazil that, in the clinical practice context of a Unified Health System oncology unit, investigated the use of ML algorithms in the prediction of early death in elderly cancer patients.

### Conflicts of Interest

None declared.

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## Abbreviations

**AUC:** area under curve  
**CGA:** Comprehensive Geriatric Assessment  
**CV:** cross-validation  
**J48:** Decision Tree  
**KPS:** Karnofsky performance scale  
**ML:** machine learning  
**MLP:** multilayer perceptron  
**MNA-SF:** Mini Nutritional Assessment-Short Form  
**NB:** Naive Bayes

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Original Paper

# Examining the Interaction Between Medical Information Seeking Online and Understanding: Exploratory Study

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## Abstract

**Background:** Online information seeking on medical topics by patients can have beneficial effects by helping them decide on treatment options and fostering better relationships with doctors. The quality of websites and processes of seeking information online have mostly been studied, with a focus on the accuracy and reliability of websites; however, few studies have examined the relationship between other aspects of quality and the processes of seeking medical information online.

**Objective:** This exploratory study aimed to shed light on the quality of websites used for information seeking from the perspective of understanding medical information in combination with seeking it online.

**Methods:** The study participants were 15 Japanese university students with no problem using the internet. A questionnaire survey about health literacy (47 items on a 4-point Likert scale) and information navigation skills on the internet (8 items on a 5-point Likert scale) was conducted before participants engaged in online information seeking and qualitative interviews. The students searched for information on a disease and its treatment. The websites viewed were gathered from search behavior recorded by software and browser logs. Follow-up interviews were conducted to elicit explanations from the participants about the assignments and their views of online information seeking. The explanations were evaluated by 55 health care professionals on a 3-point Likert scale and then assessed based on their comments and the participant interviews.

**Results:** The mean age of the participants was 20.6 years (median 21; SD 1.06). All participants were able to access reliable websites with information relevant to the assignments. The mean ratings of the students' explanations were 108.6 (median 109; range=83-134) for the disease and 105.6 (median 104; range=87-117) for its treatment. The inter-rater reliability were 0.84 (95% CI 0.77-0.90) and 0.95 (95% CI 0.93-0.97), indicating good and excellent, respectively. The mean of the sum of the health literacy skills was 115.1 (median 115; range=80-166) and the mean for information navigation skills was 25.9 (median 26; range=17-36), respectively. Health literacy and information navigation skills were moderately correlated ( $r=0.54$ ; 95% CI 0.033-0.822;  $P=.04$ ). Among the four stages of health literacy, understanding and appraising ( $r=0.53$ ; 95% CI 0.025-0.820;  $P=.04$ ) were moderately correlated with information navigation skills ( $r=0.52$ ; 95% CI 0.013-0.816;  $P=.046$ ). The participants had no difficulties operating and browsing the internet and considered medical and public institution websites to be reliable; however, due to unfamiliarity with medical terms, they had difficulties choosing a site from the results obtained and comparing and synthesizing information provided by different sites. They also looked for sites providing orderly information in plain language but provided explanations from sites that gave inadequate interpretations of information.

**Conclusions:** This study revealed interactions between searching the internet for, and understanding, medical information by analyzing the processes of information seeking online, physicians' evaluations and comments about the participants' explanations, and the participants' perceptions.

**KEYWORDS**

consumer health informatics; information-seeking behavior; internet access; health communication; health literacy

## ***Introduction***

As information becomes increasingly prevalent in modern society, patients can now gather medical and health-related information through different media, enabling them to more easily find doctors and understand treatments, which in turn affects how they interact with health care professionals [1,2]. In a review by Tan and Goonawardene, it was noticed that seeking information online can improve the doctor-patient relationship [3]. It has also been noted that “Dr Google,” which refers to seeking health and medical-related information on Google, can strengthen the relationship between information seekers and health care professionals [4]. In Japan, the internet has been ranked by cancer patients as the second most trustworthy source of information after health care professionals, indicating that a large amount of information is being gathered online and that searching for it may improve patients’ understanding of their disease, thus fostering relationships with health care professionals [5]. It has also been suggested that online information seeking may reduce the prevalence of delayed diagnoses [6].

Health and medical information on the internet have been studied from the perspectives of their accuracy, their reliability, and in terms of information seeking processes. However, the accuracy of online information is often questioned [7-11], and there are concerns that searches for online health information increase patient anxiety [12]. It has been reported that medical websites focus mainly on the quality of accuracy, not on more indirect indicators such as reliability, the provision of context, the qualifications of the authors, and the use or acceptance of information by consumers [13]. Concerning the reliability of websites, the Journal of the American Medical Association (JAMA) and the DISCERN guidelines recommend that websites should display items such as the authors, affiliations, disclosures, and currency to facilitate users’ retrieval of credible information [7,14,15]. The Health On the Net (HON) code shows that websites provide useful and reliable health and medical information online [16]. The National Institutes of Health (NIH) have provided a checklist for judging the reliability of websites based on whether the sponsor or owner of the site is a Federal agency, medical school, or large professional or nonprofit organization, is related to one of those, or if not, is sponsored by such organizations, written by a health care professional, or references trustworthy sources for its health information [17]. As an example of a health information website, MedlinePlus is well known to offer reliable information on over 1000 health-related topics [18].

In addition, the actual processes of users’ information seeking for medical information have been explored qualitatively [19-23]. These studies examined how users search the internet to find answers to given assignments. Observations with in-depth interviews showed that adults in Germany could find health information to answer questions, but their search techniques

were suboptimal [19]. Around 70% of the adolescent participants taking part in a study in the United States could find correct and useful answers to health questions [20]. Patterns of cognitive processes in medical information seeking were explored in young adults in the United States, and the results showed that dual processing (deliberate thinking) was associated with higher education levels and younger age. Health literacy has been linked to literacy and has been shown to entail:

*People’s knowledge, motivation, and competence to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life [24].*

Thus, identifying problematic areas in terms of skills may be one way of enabling sound information seeking.

The relationship between health literacy and observations on medical information seeking was also investigated. Adults with rheumatic diseases taking part in a survey in the Netherlands experienced difficulties, especially in using search strategies and evaluating the relevance and reliability of websites [22]. Concerning health literacy, Israeli adults aged 50 years and older were shown to have lower successful completion rates of seeking medical information online in the order of accessing, understanding, appraising, applying, and generating new information [23].

Although these previous studies have deepened our understanding of health and medical information seeking online, the goals of consumers searching for medical information on the internet involve not only finding the information on a disease and its treatment options, but also understanding it for themselves, their family, or close friends. Therefore, the present exploratory study attempts to address the problem of interaction between understanding information closely related to the “use or acceptance of information” [13] and searching for medical information on the internet. For this purpose, we pose the following two research questions: (1) are consumers who do not have difficulty utilizing the internet able to find websites that offer reliable medical information; and (2) are consumers who find reliable websites able to understand the relevant medical information?

Additionally, to further the discussion of this study, we also examined health literacy and information navigation skills. Based on the answers to these research questions, the present study examined the problem of the interaction between searching the internet for, and understanding, medical information, and it suggests a future direction for effective information seeking online.

## ***Methods***

### **Participants**

The study participants were recruited through a research company in Japan. The company selected a similar ratio of male

and female university students from its monitors, excluding those who were majoring in medicine. To avoid any problems associated with internet use and basic reading or writing ability, all the participants were chosen from among university students, and all the students confirmed they had no problems using the internet in everyday life. The number of participants was chosen in reference to existing studies [19,20] and the recommended rule of thumb for interview surveys [25].

Written informed consent was obtained at the beginning of the study. Personal information capable of identifying individuals was kept secure by the research company.

## Study Design

### Overview

The study was conducted in September 2017 and consisted of three stages: (1) assessing the participants' health literacy and information navigation skills on the internet; (2) observing the participants' information seeking behavior for given assignments; and (3) conducting follow-up interviews with the participants, and then rating and commenting on their explanations with a group of physicians. To exclude any influence from the search histories of other users, separate accounts were created for each participant. Stage 2 of the research was meant to answer for answering RQ1, stage 3 was meant to answer RQ2, the discussion of which is deepened with the results of stage 1.

### Stage 1

The health literacy and information navigation skills of the participants were surveyed using the translated Japanese version of the Health Literacy Scale (HLS-EU-Q47), which is composed of 47 items rated on a 4-point Likert scale from 1-4 (very easy to very difficult; inverted scale) along with 0 (don't know) [26,27], and the Information Navigation Skills on the Internet Scale [28], which is composed of eight items rated on a 5-point Likert scale from 1-5 (not at all true of me to very true of me; inverted scale).

### Stage 2

To observe the participants' information seeking behavior, they were allocated the assignments and instructed to search the internet for a maximum of 20 minutes. Eysenbach et al's search experiments took 5 min 42 secs (median 4 min 18 secs; range=38 secs-20 min) per question to find an answer [19]. Hansen et al's experiments took an average of 5 min and 41 secs and from just under a minute to nearly 24 min [20]. Perez et al's experiments took 5 minutes 8 seconds (range=55 secs-14 min 16 secs) [21]. Based on these studies, we chose 20 minutes for the assignments, expecting that this would leave ample time for the participants. The task was to explain, in an easy to understand manner to an individual with no medical knowledge, the histological types of lung cancer (nonsmall cell lung cancer), disease staging (T2a, N1, and Stage IIB), and treatment options. In Japan, smoking is legally permitted for adults over 20 years of age. Although around 50% of high school students enter universities, they are often placed in a position of deciding whether to start smoking. As the World Health Organization

has run anti-smoking campaigns regarding the risk of lung cancer, and the Olympic Games are planned for Tokyo in 2020, this anti-smoking campaign has been seen widely in Japan, giving Japanese university students opportunities to think deeply about smoking. The research team recorded information seeking processes by documenting search histories using the browser log function and screen recording software (Apower Screen Recorder Pro 2.2.4, Hong Kong). The participants bookmarked the necessary websites and took notes while seeking information.

### Stage 3

The follow-up interviews were conducted immediately after the online search for the given assignments. An interview guide that had been prepared in advance was used to ask the participants to explain the disease and its treatment options and how they perceived the online information seeking. The interviews were recorded using a digital voice recorder and then transcribed verbatim. A consumer's ability to understand information differs from that of external observers; thus, in this study, the participants explained their answers using the websites they had bookmarked and the notes they had taken while performing the search. A total of 55 thoracic surgeons rated the participants' explanations on a 3-point Likert scale, from 1 (correct) to 3 (incorrect), and then provided comments. Low-rated explanations by the participants who were able to visit the websites that had adequate information were examined based on the physicians' comments and the interviews.

All statistical computations were performed using R version 3.5.2 (The R Foundation, Vienna, Austria). This study was approved by the Institutional Review Board of the Interfaculty Initiative in Information Studies, The University of Tokyo.

## Results

### Participants

The participants consisted of seven females and eight males (mean age 20.6; median age 21; SD 1.06).

### Reliability of Websites

Table 1 summarizes the websites visited by the participants, their staying time as extracted from the logs of the browser with the captured screen records, and their ratios. The websites were classified by the first and the second authors using the scheme proposed in Goto et al [7], and all differences were resolved by discussion. The classification consists of nonprofit organizations and public institutions (PI), medical institutions (MI), pharmaceutical companies (PC), commercial companies (CC), medical professionals (MP), encyclopedias or dictionaries (ED), and unknown. Analysis of the search results using the words that appeared in the assignments revealed that the participants visited a mean of 5.9 sites (median 6; range=3-10), and their mean staying time was 177.6 secs (median 105.1 secs; range 2.33-918.4). All participants were confirmed to have reached websites matching a checklist issued by the NIH [17] for judging reliable websites, such as those sponsored or owned by a federal agency, large PI or MI, or written by a PC referencing trustworthy sources for its health information.

**Table 1.** The websites visited by the participants (P1-P15), their staying time (in seconds), and their ratios (in brackets; calculated as the ratios of staying time for respective sites divided by that for all sites).

Websites	P1 <sup>a</sup>	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15
PI <sup>b</sup> 1	— <sup>c</sup>	187.32 (20.3)	61.79 (5.9)	412.33 (36.9)	164.96 (14.0)	—	252.35 (23.7)	—	73.74 (6.7)	—	483.35 (58.8)	118.25 (10.7)	168.56 (14.8)	—	—
PI 2	86.25 (9.5)	—	—	—	—	—	—	—	289.34 (26.5)	192.95 (16.5)	—	237.53 (21.5)	793.74 (69.7)	—	269.25 (29.2)
PI 3	—	11.61 (1.3)	—	—	—	—	—	—	5.24 (0.5)	—	—	27.33 (2.5)	—	154.97 (13.2)	3.74 (0.4)
PI 4	—	55.57 (6.0)	—	—	—	—	—	—	—	—	—	—	—	—	—
PI 5	—	—	—	—	—	—	—	115.92 (10.0)	—	—	—	—	—	—	—
MI <sup>d</sup> 1	87.25 (9.6)	36.38 (3.9)	151.64 (14.4)	104.58 (9.4)	451.58 (38.3)	232.66 (23.0)	—	—	73.67 (6.7)	56.93 (4.9)	21.97 (2.7)	22.66 (2.0)	—	—	—
MI 2	—	78.84 (8.5)	—	16.92 (1.5)	423.89 (36.0)	—	—	—	24.51 (2.2)	—	—	—	—	66.05 (5.6)	105.51 (11.5)
MI 3	—	211.45 (22.9)	—	—	—	—	—	—	—	—	—	—	36.38 (3.2)	—	—
MI 4	—	—	133.27 (12.6)	—	—	—	—	—	—	—	—	—	—	—	—
MI 5	—	—	290.27 (27.5)	—	—	—	—	—	—	—	—	—	—	—	—
MI 6	—	—	—	—	—	337.91 (33.4)	—	—	—	—	—	—	—	—	—
MI 7	—	—	—	—	—	188.34 (18.6)	—	—	—	—	—	—	—	—	—
MI 8	—	—	—	—	—	—	—	—	—	—	—	261.49 (23.7)	—	—	—
PC <sup>e</sup> 1	—	306.39 (33.2)	379.49 (36.0)	438.81 (39.3)	139.05 (11.8)	251.62 (24.9)	743.11 (69.9)	903.68 (77.9)	262.3 (24.0)	918.43 (78.6)	192.64 (23.4)	330.55 (30.0)	140.86 (12.4)	215.22 (18.3)	518.05 (56.3)
PC 2	—	9.26 (1.0)	16.07 (1.5)	72.58 (6.5)	—	—	—	—	—	—	—	14.74 (1.3)	—	—	13.77 (1.5)
PC 3	—	—	—	—	—	—	31.33 (3.0)	—	67.23 (6.1)	—	88.15 (10.7)	—	—	70.33 (6.0)	—
PC 4	—	—	—	—	—	—	—	—	—	—	36.34 (4.4)	—	—	—	—
CC <sup>f</sup> 1	346.48 (38.0)	—	—	—	—	—	—	—	164.78 (15.1)	—	—	93.05 (8.4)	—	127.42 (10.8)	—
CC 2	2.33 (0.3)	—	—	—	—	—	—	—	—	—	—	—	—	—	—
CC 3	—	18.09 (2.0)	—	—	—	—	—	—	—	—	—	—	—	—	—
CC 4	—	—	22.63 (2.1)	—	—	—	—	—	—	—	—	—	—	—	—
CC 5	—	—	—	—	—	—	—	—	25.19 (2.3)	—	—	—	—	—	—



Websites	P1 <sup>a</sup>	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15
CC 6	—	—	—	—	—	—	—	—	—	—	—	—	—	541.93 (46.0)	—
CC 7	—	—	—	—	—	—	—	—	—	—	—	—	—	—	9.49 (1.0)
CC 8	—	—	—	—	—	—	—	—	107.29 (9.8)	—	—	—	—	—	—
MP <sup>g</sup>	—	—	—	—	—	—	—	48.12 (4.1)	—	—	—	—	—	—	—
ED <sup>h</sup> 1	44.01 (4.8)	—	—	—	—	—	36.53 (3.4)	—	—	—	—	—	—	—	—
ED 2	—	8.35 (1.0)	—	—	—	—	—	—	—	—	—	—	—	—	—
ED 3	—	—	—	72.66 (6.5)	—	—	—	—	—	—	—	—	—	—	—
Unknown	61.24 (6.7)	—	—	—	—	—	—	92.88 (8.0)	—	—	—	—	—	—	—

<sup>a</sup>P: participant

<sup>b</sup>PI: nonprofit organizations and public institutions

<sup>c</sup>Not applicable.

<sup>d</sup>MI: medical institutions

<sup>e</sup>PC: pharmaceutical companies

<sup>f</sup>CC: commercial companies

<sup>g</sup>MP: medical professionals

<sup>h</sup>ED: encyclopedias or dictionaries

The NIH checklist is not a detailed specification of reliable sites but a set of heuristic rules for consumers when searching for reliable medical and health information on the internet. To further check whether the websites contained sufficient information for the task, the websites that the participants visited were examined for information on diseases (nonsmall cell lung cancer, T-factor, N-factor, and staging) and treatment options (surgery, chemotherapy, and radiation). Table 2 shows that the websites recommended by the NIH did not necessarily include relevant information. However, the websites participants stayed on for the longest to second-longest and the longest to the third-longest time had requisite information for the disease and its treatment, respectively.

## Understanding Relevant Medical Information

### Ratings of the Explanations by Medical Professionals

#### Overview

The participants were interviewed after searching the internet for the given assignments, and during the interviews they explained the disease and its treatment and described their perceptions of the internet search. After that, 55 thoracic surgeons rated the correctness of the participants' explanations on a 3-point Likert scale from one (correct) to three (incorrect) and provided comments regarding the explanations. Their mean ratings were 108.6 (median 109; range=83-134; min-max [refers to theoretical range]=55-165) for the disease and 105.6 (median

104; range=87-117; min-max=55-165) for its treatment options. However, the judgments of the MP were different from coders' ratings based on a coding book. To assess the reliability of the rating, the inter-rater reliability, ICC(3,k), which is frequently utilized in computing internal consistency [29], was calculated. The reasons that the ICC(3,k) were chosen are: (1) the same set of raters are used for all subjects; (2) it is based on mean of the raters; and (3) for consistency, it is more appropriate than absolute agreement for the judgments of the MP. The results obtained were 0.84 (95% CI 0.77-0.90), indicating good, and 0.95 (95% CI 0.93-0.97), indicating excellent.

Below, low-rated participants (ie, participants who scored below average) were considered to not have any understanding of the medical information. Difficulties they faced were examined based on their interviews and the physicians' comments on their responses.

#### Explanations for the Disease

Overall, 8 participants whose explanations were rated below average were able to access websites that had information on the disease, but they were unable to extract enough information to answer the question. In the interviews, 5/8 participants expressed difficulties in understanding unfamiliar technical terms. The physicians provided comments that their explanations included inadequate information extracted from inappropriate locations on the websites and given as incorrect answers.

**Table 2.** The websites visited by the participants (P1-P15) and whether they included information about the disease and its treatment.

Websites	Disease							Treatment options		
	Non-small cell lung cancer	T-factor	T2a	N-factor	N1	Stage	Stage II B	Surgery	Chemotherapy followed by surgery	Radiation therapy for patients who cannot have surgery
PI <sup>a</sup> 1	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
PI 2	✓									
PI 3			✓	✓	✓	✓	✓	✓	✓	✓
PI 4										
PI 5	✓	✓		✓		✓		✓	✓	✓
MI <sup>b</sup> 1	✓	✓	✓	✓	✓	✓	✓	✓		✓
MI 2	✓					✓		✓	✓	✓
MI 3	✓		✓	✓	✓		✓	✓	✓	✓
MI 4	✓	✓	✓	✓				✓	✓	
MI 5	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
MI 6	✓			✓			✓	✓	✓	✓
MI 7	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
MI 8	✓		✓	✓	✓		✓	✓		✓
PC <sup>c</sup> 1	✓	✓	✓	✓	✓	✓	✓	✓	✓	
PC 2								✓	✓	✓
PC 3	✓					✓		✓	✓	
PC 4	✓									
CC <sup>d</sup> 1	✓							✓	✓	✓
CC 2						✓		✓		
CC 3	✓									
CC 4										
CC 5										
CC 6	✓			✓		✓		✓	✓	✓
CC 7	✓			✓	✓	✓		✓	✓	
CC 8						✓				
MP <sup>e</sup>										
ED <sup>f</sup> 1	✓		✓	✓		✓				
ED 2	✓		✓	✓	✓	✓	✓	✓		
ED 3	✓					✓		✓	✓	
Un-known		✓		✓	✓			✓	✓	

<sup>a</sup>PI: nonprofit organizations and public institutions<sup>b</sup>MI: medical institutions<sup>c</sup>PC: pharmaceutical companies<sup>d</sup>CC: commercial companies<sup>e</sup>MP: medical professionals<sup>f</sup>ED: encyclopedias or dictionaries

### Explanations for the Treatment Options

In total, 7 participants whose explanations were rated below average were able to access websites that had information about treatment options. However, regardless of rating, none of the participants were able to extract enough information to answer the question. Some of the websites did not include enough information for all treatment options, so the participants who visited such websites needed to synthesize information from multiple sites, which made the task more demanding. The physicians commented that the responses provided by 5/7 participants who were rated below average included either incorrect expressions or inadequate information extracted from inappropriate locations on the websites they used.

### Participants' Health Literacy and Information Navigation Skills

The mean, median, min-max, and range of the sum of the health literacy skill scores were 115.1, 115, 47-188, and 80-166, respectively, which are comparable to the results of Nakayama et al's study involving the Japanese population [27], and the mean, median, min-max, and range of the sum of the information navigation skill scores were 25.9, 26, 8-40, and 17-36, respectively. The health literacy and information navigation skills were moderately correlated ( $r=0.54$ ; 95% CI 0.033-0.822;  $P=.04$ ). Among the four stages of health literacy (accessing, understanding, appraising, and applying), understanding and appraising ( $r=0.53$ , 95% CI 0.025-0.820;  $P=.04$ ) were moderately correlated with internet literacy ( $r=0.52$ ; 95% CI 0.013-0.816;  $P=.046$ ).

## Discussion

### Reliability of Websites

The participants were able to find sites that followed the NIH guidelines and included relevant information for the assignments, but each site did not necessarily have a complete collection of information.

The participants in the present study did not report having any difficulties operating the browser or searching the internet; however, their level of health literacy was a little below the theoretical average, comparable to the results of Nakayama et al's survey on the Japanese population [27], while their level of information navigation skills was a little above the theoretical average. These results may be because of differences between self-reported and questionnaire-based health literacy. Information navigation skills on the internet were moderately correlated with understanding and appraising health literacy, which indicates that the former involves some aspect of comprehending health and medical information on the internet.

Neter and Brainin [23] showed that self-administered health literacy was moderately correlated with actual health literacy. This means that currently the former cannot be an accurate index for the latter, and thus, it is difficult to distinguish patients with low health literacy (LHL) from those with high health literacy (HHL). Furthermore, medical information for patients with LHL can be used for those with HHL, but not vice versa. Therefore, the written and online strategies reviewed by Noordman et al [30] can be used to support consumers with either LHL or HHL

to select a website, compare multiple sites, and understand information on the internet, at least until more accurate health literacy—reflecting actual behavior is developed, as noted by Neter and Brainin [23].

### Understanding Relevant Medical Information

An analysis of the physicians' ratings and comments about the explanations, as well as the interview data for the participants, revealed an interaction between information seeking online and understanding. That is, even if the participants visited the websites of a PI or MI that provided correct medical information, they would go to another site to obtain the same information explained simply, but then they would process this information inadequately. These participants did not have enough knowledge to understand medical information, they had trouble sifting through the large number of search results, and they found it difficult to compare and synthesize information from different sites to obtain answers to their medical questions.

Noordman et al reviewed several strategies and tools for health care professionals to support patients with LHL in hospital-based palliative care settings [30]. The written and online strategies were classified into those related to content (providing information in lay terminology and developing test material for the target population) and those related to representation (the use of graphs and illustrations, font size and spacing, and the length of sentences and paragraphs). They suggested that the strategies and tools were not specific to the palliative care setting for patients with LHL.

The findings of this study regarding the interaction between information seeking online and understanding medical information suggest the possibility of considering the quality of medical information from the viewpoint of understanding it, in combination with the process of information seeking. Pallotti et al's study to integrate the readability of a website into their search ranking algorithm [31] can be considered a step in this direction.

Evaluating consumers' understanding is not a simple task. The assessments carried out by the physicians in the present study are too costly to apply. Instead, test materials for information on a website, as suggested by Noordman et al, may be a tool for consumers to self-check whether they can grasp the level of information. Eysenbach and Diepgen proposed self-labelling of medical information by website authors with a systematic evaluation of health-related information by users and third parties using a legitimized standard vocabulary [13]. Their proposal has not been widely used; however, the test materials may be an approximate substitute for website authors' self-labels, in that consumers are able to judge a website by reviewing these as a kind of summary instead of viewing the complete information.

### Limitations

Qualitative studies and quantitative studies are complementary: the former can examine the details of phenomena and propose assumptions consisting of novel concepts and their relationships (although these need to be generalized), whereas the latter can verify a theory based on statistics, although this sometimes involves assumptions that are not free from questions regarding

the validity of statistical inferences. This dichotomy of characterization may be coarse, but it is unavoidable that both approaches are necessary to advance research.

As this was only an exploratory study, further research with more diverse participants and assignments is needed to increase the generalizability of the findings. Furthermore, those who search for medical information online sometimes engage in

information seeking because of a vague sense of unease without having a clear sense of what they are searching for. In the present study, the participants had a clear sense of what they were searching for and therefore, future studies could explore the search behaviors of individuals who do not. In addition, future research should include test materials for a website prepared to examine how to assist consumers with internet searching.

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## Conflicts of Interest

None declared.

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## Abbreviations

- CC:** commercial companies
- ED:** encyclopedias/dictionaries
- HHL:** high health literacy
- HLS:** health literacy scale
- HON:** Health On the Net
- ICC (3,k):** intraclass correlation coefficient (3,k)
- JAMA:** Journal of the American Medical Association
- LHL:** low health literacy
- MI:** medical institutions
- MP:** medical professionals
- NIH:** The National Institutes of Health

**PC:** pharmaceutical companies

**PI:** nonprofit organizations and public institutions

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Original Paper

# Experiences of Using a Consumer-Based Mobile Meditation App to Improve Fatigue in Myeloproliferative Patients: Qualitative Study

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## Abstract

**Background:** Myeloproliferative neoplasm (MPN) patients suffer from long-term symptoms and reduced quality of life. Mindfulness meditation is a complementary therapy shown to be beneficial for alleviating a range of cancer-related symptoms; however, in-person meditation interventions are difficult for cancer patients to attend. Meditation via a mobile phone app represents a novel approach in MPN patients for delivering meditation.

**Objective:** The study aimed to report MPN patients' (ie, naïve or nearly naïve meditators) perceptions of meditation and explore their experiences in the context of using a mobile phone for meditation after participation in an 8-week consumer-based meditation app feasibility study.

**Methods:** MPN patients (n=128) were recruited nationally through organizational partners and social media. Eligible and consented patients were enrolled into 1 of 4 groups, 2 that received varying orders of 2 consumer-based apps (*10% Happier* and *Calm*) and 2 that received one of the apps alone for the second 4 weeks of the 8-week intervention after an educational control condition. Participants were asked to perform 10 min per day of mobile phone-based meditation, irrespective of the app and order in which they received the apps. At the conclusion of the study, participants were asked whether they would like to participate in a 20-min phone interview comprising 9 to 10 questions to discuss their perceptions and experiences while using the mobile phone meditation apps. The interviews were transcribed verbatim and imported into NVivo 12 (QSR International) for coding and analysis, using a combination of deductive and inductive methods to organize the data, generate categories, and develop themes and subthemes.

**Results:** A total of 48 MPN patients completed postintervention interviews, of which 29% (14/48) of the patients only used the *10% Happier* app, 21% (10/48) of the patients only used the *Calm* app, and 46% (22/48) of the patients used both apps during the 8-week intervention. Themes identified in the analysis of interview data related to (1) perceptions of meditation before, during, and after the study, (2) perceptions of the *Calm* app, (3) perceptions of the *10% Happier* app, (4) perceived impacts of using the meditation apps, (5) overall experiences of participating in the study, (6) recommendations surrounding meditation for other MPN patients, and (7) plans to continue meditation.

**Conclusions:** The qualitative findings of this study suggest that MPN patients who are naïve or nearly naïve meditators perceived mobile phone meditation as enjoyable, preferred the *Calm* app over the *10% Happier* app, perceived the *Calm* app as more appealing (eg, narrator's voice and different meditations or background sounds offered), and perceived beneficial effects of meditation on mental health, sleep, fatigue, and pain. Future research is needed to better understand the efficacy of mobile phone meditation on MPN patient outcomes and meditation app design features that enhance uptake among its users.

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**KEYWORDS**

mindfulness; meditation; mobile phone; mHealth; digital health; cancer

## Introduction

### Background

Myeloproliferative neoplasms (MPNs) are rare hematological cancers (polycythemia vera, essential thrombocythemia, and myelofibrosis), with a chronic symptom burden that often includes fatigue, sleep disturbances, and depressive and anxiety-related symptoms, to name a few [1,2]. The only potentially curative option is allogeneic stem-cell transplantation, but it is reserved for high-risk myelofibrosis patients. Moreover, the current best available pharmacologic therapy does not completely resolve symptoms, and other standard-of-care treatments for MPN are associated with worsened fatigue, inactivity, and a reduced quality of life [3]. Despite this, patients often have a favorable life expectancy (unique compared with most malignancies), with as much as two-third of MPN patients living up to 15 years after diagnosis and some with the same life expectancy as the general population, rendering MPN a *chronic* cancer condition [4,5]. There is a need to examine complementary approaches in MPNs as a method of self-management of symptom burden for patients.

Mindfulness meditation has gained increasing attention as a complementary therapy for chronic cancer patients, particularly for alleviating a range of symptoms associated with cancer and its treatment (eg, fatigue, emotional distress, and sleep disturbances) [6-8]. Mindfulness meditation is the practice of moment-to-moment awareness, in which the person purposefully focuses on the present moment, without judgement [9,10]. However, there has been minimal research investigating the effects of mindfulness meditation as a complementary therapy in hematological cancer patients, and more specifically, only 1 small feasibility study has been conducted in MPN patients [11,12].

Participating in meditation for anxiety and stress reduction and quality of life in cancer patients is recommended by The Society of Integrative Oncology Clinical Practice Guidelines [13]. However, meditation interventions are often delivered in person (as opposed to home based or remotely), which presents many limitations [14]. In 2017, Gowin et al [15] conducted a survey in MPN patients (n=1676), and 18.97% (318/1676) of the patients reported trying meditation for the management of symptoms, but they said it was burdensome to travel to attend the face-to-face classes. MPN patients face many demands and stressors, feel overwhelmed, are fatigued, are often reluctant to take on commitments for attending and engaging in in-person interventions, and often seek treatment outside of their home city or state (ie, lack of nearby specialized treatment centers) [16,17]. Even when delivery of meditation is virtual or remote, limitations still exist, including the following: (1) there is attendance to a specific weekly schedule, (2) *meditation* programs (ie, mindfulness-based stress reduction) are comprehensive and can be potentially burdensome (90-min sessions, 8-12 weeks long) [18], and (3) traditional mindfulness meditation programs are typically delivered by trained providers,

which may be costly and not covered by insurance. There is a need to establish effective modes of delivering mindfulness meditation to chronic cancer patients, such as MPN patients.

Mobile health (the use of mobile wireless technologies for health) [19] has become a topic of considerable interest among cancer patients as a means of promoting self-management of chronic disease for better health outcomes [20]. Most cancer patients own a mobile phone, regularly use mobile apps, and are interested in accessing supportive care information via a mobile app [21,22]. In a recent survey of 1300 cancer patients, 71.00% (923/1300) of the patients reported owning a mobile phone [21]. In a 2018 survey of 631 cancer patients, 74.0% (467/631) of the patients reported regular use of a mobile phone, and 38.9% (246/631) of the patients expressed an interest in supportive care information via mobile apps [22]. In a pilot study conducted by Huberty and colleagues, 96.9% (308/318) of MPN patients indicated that they owned a mobile phone and were willing to download a mobile app to participate in app-based meditation [12]. There are approximately 300 cancer-specific apps available across the major mobile phone platforms (eg, iPhone, Android); however, a majority of available apps have limited evidence to demonstrate their effectiveness and utility, and the evidence of the clinical benefits of commercially available apps for cancer patients is in its infancy [20,23]. Despite minimal evidence in cancer patients, there have been some recent advances in the evidence base, supporting mobile phone-based meditation for health-related outcomes. A recent study conducted by Economides et al [24] investigated the effects of meditation delivered using the Headspace app on stress, affect, and irritability in novice meditators as compared with an active control (ie, audiobook delivered via Headspace app), and they found that participants in the meditation group (n=41) averaged approximately 44 min/week of meditation when asked to complete a total of 10 introductory, 10-min meditations as they desired. Furthermore, participants also saw significant improvements in irritability (Cohen  $d=0.44$ ), affect (Cohen  $d=0.47$ ), and stress (Cohen  $d=0.45$ ) compared with the active control group (n=28). Another recent study conducted by Bostock et al [25] examined the effects of a 45-day (approximately 6.5 weeks) Headspace meditation app intervention on work stress and well-being in healthy workers (n=128) compared with a wait-list control group (n=121), and they found that participants averaged approximately 42 min/week of meditation alongside significant improvements over 45 days in well-being, anxiety symptoms, depressive symptoms, and job strain compared with the control group. Despite the promising findings demonstrated by these aforementioned studies, they were both of relatively short durations (approximately 2 weeks-6.5 weeks), were not powered to determine efficacy, and did not report on features and experiences of users that were most desired for continued participation and engagement with the app. The features, functionality, and experience desired by users of mobile phone-based meditation apps have yet to be thoroughly investigated and reported. A recently published study, Huberty



et al [12], investigating the feasibility of mobile phone-based meditation via the *Calm* app and the *10% Happier* app among MPN patients demonstrated the *Calm* app to be more feasible to implement because of higher demand and acceptability. In addition, this study demonstrated limited efficacy, with small effects observed in both apps on anxiety, depression, sleep disturbance, and total symptom burden. This study illuminated some of the aspects of the *Calm* app that may have accounted for the higher demand and acceptability compared with the *10% Happier* app (eg, better app esthetics, more soothing meditation narrator voice); however, more detailed qualitative findings are needed to better understand what features and experience users desire when meditating with a mobile phone app.

## Objectives

Considering the potential benefits of meditation on cancer symptoms, the difficulty for MPN patients to attend in-person meditation interventions, the increasing prevalence of cancer-specific mobile phone apps, and the ease of accessibility to potentially efficacious interventions for symptom management, MPNs are an ideal chronic cancer population with which to gather perceptions and experiences of participation in a consumer-based mobile phone meditation intervention. The aim of this study was to report MPN patients' (ie, naïve or nearly naïve meditators) perceptions of meditation and explore their experiences in the context of using a mobile phone for meditation after participation in an 8-week, consumer-based meditation app feasibility study. Data presented here will inform the selection of an app for a future efficacy intervention in cancer patients and may provide useful information for content and design features for future meditation apps targeted at cancer patients.

## Methods

### Study Design

Participants were MPN patients who participated in a 4-group, randomized controlled trial, with a cross-over study design to examine the feasibility and limited efficacy of 2 different consumer-based meditation mobile phone apps in MPN patients: *Calm* and *10% Happier*. We used the *Calm* app for this study, as *Calm* is one of the most popular consumer-based mobile apps (ie, Apple's app of the year in 2017), the team developed a relationship with *Calm* to conduct research using the app, and *Calm* agreed to provide the memberships to the app and share the tracking data with the research team, without cost. The *10% Happier* app was chosen, as the app was one of the competing meditation mobile apps of *Calm*, and *10% Happier* also agreed to provide the memberships to the app and share the tracking data with the research team, without cost. Both mobile phone apps are available across all major mobile phone platforms (ie, Android and iOS). Both the *Calm* app and *10% Happier* app were developed for the general population and not necessarily for a particular chronically ill population. In addition, both of these apps have a free option with limited accessibility, as well as a paid option with full accessibility. The findings and a detailed overview of the methods from the feasibility study are reported elsewhere in the parent paper [12] (ClinicalTrials.gov, NCT03726944). Briefly, participants were randomly assigned

to 1 of 4 different groups that each comprised 2 different conditions lasting 4 weeks each. Group #1 received the *10% Happier* app, followed by the *Calm* app; Group #2 received the *Calm* app, followed by the *10% Happier* app; Group #3 received an educational control condition, followed by the *10% Happier* app, and Group #4 received an educational control condition, followed by the *Calm* app. When participating in a meditation app condition, participants were asked to meditate for 10 min/day on each day of the week. Those in the educational control condition received a handout describing evidence-based fatigue management strategies. All participants had autonomy to use the app as they desired after completing the prescribed daily meditation. Each app housed a library of meditations and content from which participants could choose. Emails were sent to all participants at the beginning of each week to remind them to meditate (ie, use the app). The qualitative portion of the study was designed to explore the perceptions of MPN patients practicing meditation either for the first time or as fairly inexperienced users and to explore their experiences in the context of mobile phone delivery.

### Recruitment

MPN patients (n=128) were recruited on the Web through MPN organizational partners, with a flier outlining the study and its requirements. The study was advertised as a mobile phone app meditation study. MPN patients interested in the study were asked to complete a Web-based eligibility questionnaire, administered via Qualtrics (Provo, UT), and if eligible, a phone call was arranged by the staff to complete informed consent, followed by electronic signature. Patients were eligible if they (1) had a diagnosis of essential thrombocythemia, polycythemia vera, or myelofibrosis, (2) owned a mobile phone and were willing to download and use a meditation app, (3) could read and understand English, (4) were aged 18 years or older, (5) were willing to be randomized to 1 of 4 different groups, (6) were not regular meditators (ie, engaged in <10 min/day of meditation on <5 days/week for the past 6 months), (7) were not regularly engaged in tai chi, qigong, or yoga (ie, engaged in >60 min/week each week), (8) were neither currently using the *Calm* app nor the *10% Happier* app, and (10) were currently residing in the United States.

### The *Calm* App

The *Calm* app was downloaded onto the participant's mobile phone, and the app was available to those with an iPhone or an Android phone. The *Calm* app's introduction to meditation incorporated basic, educational information for those new to meditation, while introducing brief experiential practices. Daily meditations were called the Daily *Calm*, and these were new and unique, provided by the app each day. The daily meditations had a different focus (eg, practicing patience, loving, kindness, and gratitude), and these were approximately 10 to 12 min in length. Meditations were also selected from a library of meditations with the app. In addition, the *Calm* app also offered other features, such as Breathe Bubble, Sleep Stories, *Calm* Body, *Calm* Music, *Calm* Masterclass, and Background Scenes. *Calm* provided researchers with the usage data for each study participant (ie, number of minutes; see Figure 1).

**Figure 1.** The *Calm* app.

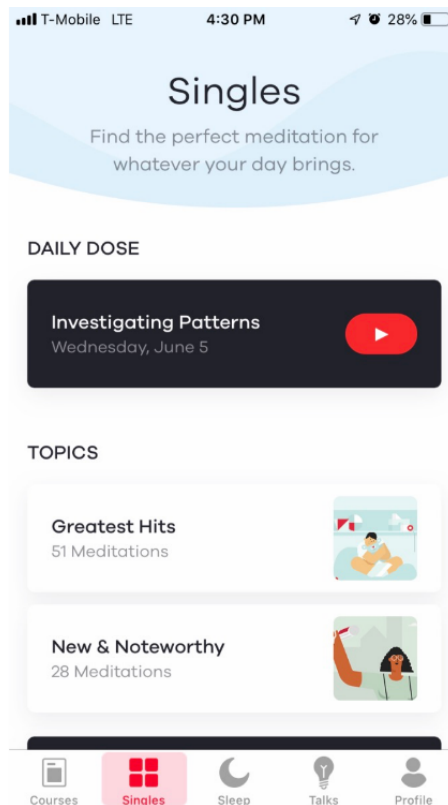


**The 10% Happier App**

The *10% Happier* app was downloaded onto the participant’s mobile phone, and the app was available to those with an iPhone or an Android phone. The *10% Happier* app’s introduction to meditation incorporated basic information for those new to meditation. Daily meditations were selected from a library of

meditations included within the app. Each of the meditations had a different focus (eg, grief, gratitude, choice, and letting go), and these were approximately 10 to 12 min in length. *10% Happier* primarily offers individual, guided meditations and short courses (eg, Meditation for Skeptics, Phrases for Stress). *10% Happier* provided researchers with the usage data for each study participant (ie, number of minutes; see [Figure 2](#)).

**Figure 2.** The *10% Happier* app.



## Qualitative Interview Procedures

At the end of the 8-week feasibility study [12], participants were given an option to participate in a 15-20-min telephone interview, conducted by trained student research assistants. Before conducting each interview, the research assistants explained the purpose, the amount of time the interview would take, and the voluntary nature of participation (ie, the participant's ability to skip questions or end the interview at any time). The interview questions, as shown in Table 1, were developed by the research team to determine perceptions and explore experiences in the context of mobile phone delivery of meditation, as well as provide further insights into how such interventions might be beneficial for the target population.

A semistructured interview script was used for each interview, including open-ended questions and additional probe questions to garner further information from the study participants. Although some probe questions were predefined (see Table 1), interviewers were also free to ask additional questions for clarification or expansion of the specific responses provided by participants. The relatively short and semistructured approach to qualitative data collection allowed for the interviews to remain focused while being open and flexible for participants to describe their experiences [26,27] of using the meditation apps from their personal perspectives and in their own words. With the permission of participants, all interviews were audio recorded for transcription.

All interview transcripts were imported into NVivo 12 (QSR International) for coding and analysis, using a combination of deductive and inductive methods to organize the data, generate categories, and develop themes and subthemes [28,29]. Braun et al [26] describe thematic analysis as “a method for identifying,

analyzing, and reporting patterns (themes) within data” (page 6). It is not bound to any particular theoretical framework, and it can therefore be used flexibly within a range of different epistemological and ontological perspectives. The hybrid deductive and inductive approach to thematic analysis used in this study reflects the thematic analysis approach described by Braun et al [26] and Swain et al [27], in which both the existing knowledge and understanding of the researcher, as well as the semantic content of the research data, are involved in developing codes to represent particular constructs. We used a semistructured approach to data collection, in which the raw interview data naturally fell into a number of higher-level themes related to the predefined questions or structured aspects of the interviews. Within these higher-level themes, inductive thematic analysis methods were used to identify relevant lower-level codes or constructs from the transcribed raw interview data, with chunks of data being assigned to codes and labeled to reflect their meaning [26]. The overall coding process, which was carried out by a highly experienced qualitative research specialist and member of the research team, involved an iterative process, with several stages in which codes and their corresponding labels were reviewed, revised, and in many cases, grouped or categorized within intermediate-level codes or themes. This continued until the overall distribution and definition of themes and subthemes were felt to most accurately reflect the body of research data and the reported experiences of the participants. The findings of the study are reported by key themes below and illustrated by verbatim quotes from the interviews to convey the real-life experiences of the participants. Quantitative counts of the numbers of participants reporting particular types of views on or experiences of the meditation intervention are included in tables and the narrative in a summative style of analysis.

**Table 1.** Interview questions.

Number	Question
1	Which meditation app or apps did you use during your participation in this study?
2	If both Calm App and 10% Happier App were used, which meditation app did you prefer or enjoy more and why?
3	What did you like most about using this app or these meditation apps?
4	What did you like least about using this app or these meditation apps?
5	How do you feel that participating in meditation has impacted you?
Probe	Fatigue levels? Sleep quality? Self-esteem? Mental well-being? Overall health?
6	Have you noticed any other changes in your life that might be associated with your participation in meditation?
7	Before starting this study, how did you feel about meditation?
Probe	Had you ever participated in meditation before?
8	Now that you have completed this study, how do you feel about meditation?
Probe	Do you think you will continue to meditate moving forward? If yes, why do you think you will continue meditating moving forward? If no, is there anything that would encourage you to continue meditating? Are there any other complementary approaches that you are interested in trying? (Tai Chi? Qi Gong? Massage?)
9	If another MPN <sup>a</sup> patient asked you what you thought about him or her participating in meditation, what advice would you give?

<sup>a</sup>MPN: myeloproliferative neoplasm.

## Approval and Consent

This study was approved by the Institutional Review Board at Arizona State University, and all participants signed an informed consent before participating in the study.

## Results

### Characteristics of Study Participants

The total sample included 48 MPN patients. Participants were aged 59 (SD 10) years, had a body mass index of 27 (SD 6) kg/m<sup>2</sup>, and were primarily female (73%; 35/48) and Caucasian (94%; 45/48). In addition, the majority of participants had an annual income >US \$61,000 (60%; 29/48), had a Bachelor's degree or higher (69%; 33/48), and were married (81%; 39/48). The most common MPN diagnosis was polycythemia vera (42%; 20/48), followed by essential thrombocythemia (33%; 16/48) and myelofibrosis (25%; 12/48). Most were diagnosed >3 years ago (58%; 28/48). Across demographic variables, most were comparable to what is typically seen in MPN patients, with the exception of the majority being female (approximately 50%-55% female is the typical proportion in MPNs) [1]. Fatigue at baseline averaged approximately 5.9 (on a scale of 0-10; 0=absent; 10=worst imaginable) and total symptom burden at baseline, as measured with the validated MPN Symptom Assessment Form Total Symptom Score (MPN-SAF TSS), averaged approximately 39.4 (on scale of 0-100; higher score indicating greater symptom burden). These baseline scores were slightly higher than what is typically seen in MPN patients (mean fatigue score is approximately 4.0-4.5, and mean MPN-SAF TSS is approximately 20.0-25.0) [1]. Upon completion of the study, weekly meditation participation averaged approximately 99 min/week for those who participated in the *Calm* app and approximately 36 min/week for those who participated in the *10% Happier* app. A total of 68% (22/32) and 20% (7/36) of *Calm* and *10% Happier* participants, respectively, averaged >70 min/week of meditation (70 min/week was prescribed). A total of 22 participants used both the *Calm* and *10% Happier* apps, 10 participants only used the *Calm* app, and 14 participants only used the *10% Happier* app. Note that not all participants were asked or did not provide an answer to the same questions. Therefore, total frequencies (n=46) do not equate to total sample size (n=48) of this study.

### Experiences and Perceptions of Meditation Before the Study

A majority of participants (60%; 29/48) reported some previous experience with meditation before participating in this study, although as a cutoff for inclusion in the study, participants could not have meditated more than 10 min/day on more than 5 days/week in the previous 6 months [12]. However, despite the high proportion of patients who had some experience with meditation in the past, less than half of the qualitative study participants (44%; 21/48) indicated that they were open minded about meditation (ie, willing to learn about meditation). Although some participants indicated that they were willing to learn about whether meditation might be beneficial for them personally, others reported that they had never been interested or had never given meditation much thought:

*I had no idea how it was going to affect me, or...whether I was going to like it or not, whether I was going to be able to do it.*

In fact, 19% of the sample (9/48) indicated that they had negative preconceptions or concerns about participating in meditation, such as the belief that they would not be able to clear their mind effectively or that the sessions would be long and tedious. Some held the unrealistic idea that the goal of meditation is to sit cross legged like a Buddhist monk or to achieve a completely blank mind:

*I (had) that preconceived thing of, you know, people sitting there with their legs crossed humming.*

*The idea of turning, kind of turning the world off or my mind off for a block of time seemed really unrealistic.*

Other types of concerns reported by some of the participants are related to the fear that others (egg, peers, friends, and family) would find them weird for meditating or that they would be vulnerable to subliminal messages in the meditation recordings:

*I have heard of meditation classes...you would sit and listen to someone talk or describe breathing and it would be half hour or an hour and I thought that was kind of a long span to kind of sit there and just mellow out.*

*(I) always worry about...subliminal messages in meditation. Because you're opening your mind so much...I always feel cautious and I am guarded.*

### Perceptions of Meditation After the Study

After participating in the study, a majority of participants expressed the view that they had enjoyed using the meditation apps, with a considerable number (17/48) reporting that their perceptions of meditation had improved or become more positive as a result of the study. Their responses indicated that there were 2 main reasons for becoming more positive about meditation as a result of participating in the study. First, some of the participants indicated that the practice of meditation had proved to be easier than they had expected and that it was not necessary to totally clear the mind during meditation or allocate a lot of time to the practice:

*If your mind starts thinking about things that's totally okay...that's totally normal...don't expect to be perfect, I mean it was just so much reassurance about how much of a learning curve is involved.*

*It doesn't have to be a chunk of time, it can just be a few minutes here or there and that's what for me really clicked and made me realize, I don't have to block off a chunk of time, it can be bits of time here and there...and that for me made it seem more realistic and reasonable.*

Others indicated that their stereotypical ideas about meditation had been broken down, as they realized that it is a practice that everyone can benefit from:

*I didn't picture it like a cult, but when you think of meditation, that's kind of what you think of. And it wasn't, at all...You know, it's just a way to calm*

*yourself down, which I think is very beneficial. So, it was nice, I mean, it's pretty much something anybody can do.*

*It was very simplistic and very easy and it didn't have anything to do with - you know - some of this some of this other stuff...the gurus I guess...some of the meditation things that you'd see on TV.*

Some participants indicated that they felt more positive about meditation as a result of experiencing direct benefits from it, such as feeling more calm or relaxed or being able to manage their pain better:

*I never believed in meditation, but in medication, and now it's different...It does work.*

*It was kind of nice to...be able to just relax and kind of let go.*

A few participants also commented that they had enjoyed the flexibility of being able to meditate anywhere, including alone at home, without having to go to a class:

*I had (a) procedure three hours away in Portland...So that was cool that I was able to take it with me.*

*I don't get to get out very much... the thing I like the best about this is that I can just do it at home ...*

As a result of these improved perceptions of meditation, a majority of the study participants (41/48) indicated that they intended or were at least considering continuing their meditation practice after the end of the study or were already doing so. More than half of all participants (29/48) reported that they planned to continue meditating with one of the study apps at least for the remainder of the free trial period, and some were considering paid subscription options for when this came to an end. Others (16/48) indicated that they do plan to continue meditating, but they planned on continuing by using different apps, meditating independently without the use of an app, or attending a class. For some, participating in the study had either given them a new or renewed interest in meditation or provided them with methods through which they planned to continue using without the app itself. A range of reasons were given for continuing meditation, such as experiencing the benefits, being able to meditate even when going through periods of severe illness, managing pain, or helping them sleep. A participant wanted to continue in preparation for future times when the participant's condition might worsen and the participant would use meditation to help manage symptoms. Only 5 participants indicated that they were not likely to continue using the apps or meditating at all. All participants indicated that they would recommend that MPN patients should at least try mobile phone meditation. A participant expressed the view that it is important for MPN patients to exert an element of control over the sense of worry and lack of control that comes with having an MPN and that meditation practice could help provide this. Others felt that meditation was worth a try, as it was not very difficult to do and had the potential to calm emotions, ease day-to-day concerns, relieve stress, or improve sleep:

*The idea of totally emptying your mind relieved a lot of worries so it's worth trying.*

*There's a constant low-grade anxiety that comes along with it (MPN), and honestly the meditation helps with that a lot.*

*For anybody who does have fatigue, I think it will help you settle yourself down and maybe improve the quality of sleep. So...yeah so, I would say go for it.*

## Perceptions of the Calm and 10% Happier Apps

### Overall Perceptions of the Apps

In general, mobile phone-guided meditation was well accepted and liked among the participants, and factors, such as the length of the meditations and the instructional content, seemed to contribute to the participants' enjoyment of both apps. Most participants who expressed a view on the issue agreed that the level of instruction in the apps was suitable for beginners:

*I had never done meditation...I felt she really did a good job of teaching me how to do it and it didn't take me long to catch on. [Calm]*

*I liked what they call the basics, the, the sixteen-course introduction to meditation...I thought those were very informative and helpful. [10% Happier]*

With regard to length of the meditations, only 10% (5/48) of the sample commented that they would have preferred the length to be different (ie, longer or shorter). It seemed that most participants felt that a commitment of 10 min of meditation was not too big of a time commitment and long enough to feel accomplished when done, but they felt that it was not so long that they became impatient for the meditation to end:

*Ten minutes wasn't a big amount of time commitment and it seemed really adequate and there was a feeling of success.*

*I think the ten-minute ones are really good. It's enough to kind of settle yourself down, and kind of get into it, but yet, you're not thinking 'oh my gosh, how much longer is this going on.'*

Of those who were more dissatisfied with the length of meditations, some mentioned that they would have preferred shorter sessions at first, whereas others would have liked to see a steady progression in length throughout the study:

*When you first start out...I think they need to be shorter...because your brain, isn't wrapped around what you're doing...so, you know, I would find myself losing focus, really quick.*

*I think I would have liked them to...every week maybe add a few minutes...so that we went from maybe ten to maybe twenty.*

A total of 7 of the participants who used both apps expressed their views, indicating that they liked both apps equally or felt that they complemented each other well; therefore, they indicated not preferring a single app. Many of their comments suggested that the 10% Happier app was seen by them as providing a better introduction to meditation, whereas Calm built on this with more effective meditation techniques.

### **Perceptions of the Calm App**

Of those participants who expressed a preference for one app over the other, a majority (91%; 20/22) expressed a preference for the *Calm* app. The main reasons for participants preferring the *Calm* app included the soothing nature of the narrator's voice, the calming background sounds on the app, and its overall appealing nature and layout:

*It was very relaxing. In fact, like, it would put me to sleep in five minutes.*

*I set it to do ocean sounds during the meditation. Which I think really helped me as opposed to the other one was just - kind of like dead air.*

*Not only do I like the things that they're saying but...the pictures that they have...you can just get lost in those things [laughs]...it totally sets you up to be calm.*

Several reported that they especially liked the Sleep Stories or other stories included in the *Calm* app, and they found them to be meaningful or relaxing:

*The stories at the end...some of them really touched me a lot and I kind of want to go back and hear them again because I want to keep...the focus of what things are all about in my mind. So as the day goes on I can remember what's really important.*

Participants who preferred the *Calm* app also referred to the wide range of meditations and the options available to pick and choose these or to tailor the app to their own preferences:

*I was...really impressed...by how many choices and different types of anxiety or sleep or whatever your choice would be, there's things available and...different backgrounds and different music...*

*I liked that I could customize for the background noise and for the wallpaper*

### **Perceptions of the 10% Happier App**

The minority (27%; 6/22) of those who had used both apps expressed a preference for *10% Happier* over *Calm*. Of these, some indicated that they had preferred the personal style of the narrator and found they could relate to his experience, whereas others liked the intellectual content and tone of this app and felt they had learned a lot about meditation from the app. A total of

3 participants who had used *Calm* first and then the *10% Happier* app said that the initial meditation videos within the *10% Happier* app would have provided a better introduction to meditation. Among the participants as a whole, including those who had only used *10% Happier* and those who had used both apps, the types of features liked about *10% Happier* included the way in which it provided a good introduction to meditation for nonexperienced meditators: the relatability of the narrator's style, the informative, educational style of the app, and the wide range of meditation topics available for selection. Overall, 12 participants made positive comments about the introductory videos included in *10% Happier*, indicating that they were interesting and a good lead into the meditations. However, some noted that they skipped these introductory videos, as they were felt to be unnecessary and even tedious once the participants were familiar with the meditation techniques:

*They were good at first, but then it was really kind of dull. It was like, alright, guys, I don't need this, let's move on.*

Some participants indicated that they disliked some of the narrative voices used in *10% Happier* and that they were "put off" by the narrator's personality or "put off" by the overall style of the narratives, which they found too impersonal:

*I had a hard time getting into him...it was just the...the way he talked...it just wasn't right for me.*

*They used the word "the" instead of "your", and I feel that meditation is a real personal sort of a thing...Calm would address me personally, even though it's an electronic device. But...the other one would use "the", it would seem very impersonal. So, I just didn't connect with it.*

Others disliked the fact that there were no background sounds in between segments of the narrative, and they preferred the calming sound effects used in the *Calm* app:

*I kept sitting there waiting for something else...you weren't sure when he was going to stop talking and start talking again.*

*It was complete silence and I didn't know if I'd been disconnected or if I'd fallen asleep or if it was over.*

The main likes and dislikes of the *10% Happier* app are shown in [Table 2](#) by numbers of participants citing each type of factor.

**Table 2.** Views on the *Calm* and *10% Happier* apps by number of participants citing each type of factor.

Factor by category	<i>Calm</i> , n	<i>10% Happier</i> , n
<b>Main likes</b>		
Introductory videos	— <sup>a</sup>	6
Range of topics or background sounds	11	4
Overall format and ease of use	8	0
Effectiveness in promoting meditative state	8	0
Narrator's voice or personal narrative	6	6
Effectiveness/quality of information	5	5
Stories	5	—
Length of meditations	4	0
<b>Main dislikes</b>		
Technical/navigation features	5	4
Background sounds/soundtracks	4	10
Too much talking/overall style	2	6
Style or limited variety of narration	2	6
Content of meditations	2	2

<sup>a</sup>Not applicable.

### Perceived Impacts of Using the Meditation Apps

A total of 25% (12/48) of participants reported no perceived benefits of meditation on their health. However, a majority indicated that use of the meditation apps had a positive impact on various aspects of their mental or physical well-being. Improvements in mental health were the most commonly cited benefits of using the apps. More than half of the sample (26/48) reported a positive impact on their ability to manage stress or anxiety, 13 participants indicated that meditation helped them feel calmer or more focused, and 8 participants reported an improved sense of general well-being since participating in the meditation study. Those who reported an impact on their ability to manage stress or anxiety highlighted ways in which the tools or strategies they had learned from the apps, such as focusing on breathing, had helped them in stressful situations or the ways in which meditation had helped them deal with worries about their condition:

*I got some stuff going on at work that's really frustrating and there were times at work that I would just sit down and close my eyes and concentrate on my breathing.*

*I had to have an MRI and I completely used the meditation while I was in the MRI and it worked. And it helped me, it was amazing.*

Others discussed ways in which they were feeling calmer or more focused in their lives as a result of the meditation practice,

or they referred to a general improved sense of mental well-being:

*I think I learned a little bit about...focusing on getting interfering thoughts out of my head*

*It just leads to being a lot more focused...And a lot more attentive I think with everything.*

*I think it puts me in a better frame of mind.*

In addition, 44% (21/48) of the participants reported improvements in sleep, resulting from the meditation practice, including an improvement in sleep quality, as well as falling asleep more quickly. Some mentioned the sleep-focused meditations and stories on the *Calm* apps as being particularly helpful for better sleep:

*Once I started meditating, it seemed to make a real shift there so that I would be able to go to back to bed and go back to sleep. And, and so I would wake up more refreshed in the morning.*

*The sleep stories were especially good...Yeah, they really do help me just focus on something, I guess, and helped me go to sleep.*

Many of those who said they were falling asleep faster were deliberately using their meditation practice at bedtime for this reason, whether or not they usually had problems falling asleep:

*I was using it to help me fall asleep because at night time I, I find that I don't sleep well, I can't fall asleep, so I found it very soothing and comforting.*

**Table 3.** Number of participants reporting positive impacts.

Factor	n
Managing stress or anxiety better	26
Easier to fall asleep	21
Better quality of sleep	21
Feeling calmer or more focused	13
Reduced fatigue	11
Improved sense of well-being in general	8
Ability to manage pain	4

Although 9 participants reported no impact on quality of sleep, in some cases, this was because of the fact they were not experiencing sleep problems when they began. Similarly, although not all participants were experiencing fatigue as one of their symptoms, 23% (11/48) of the participants reported improvements in fatigue as a result of meditation. For some, this was because of the fact that meditation helped them sleep better so that they were less tired during daytime, whereas others felt that the meditation schedule just enabled them to take a rest break, which helped recharge their energy.

*I've had more energy too, and again, you know it's that because I'm sleeping better.*

*I think there are times when I thought "Oh I could lay down, I could take a nap" and I would just lay down and listen to a meditation and you know feel more relaxed and that eased and then get up and function, you know?...I think it gave me that break where ok you can take time out of your day and do a little meditation and then maybe you feel like you can get up and do things.*

Finally, 8% (4/48) of the participants reported that meditation had been helpful in reducing or helping them manage pain.

*I have noticed if I started meditating and had a headache, the headache seemed to go away.*

Some participants who reported perceived impacts of meditation on various aspects of their physical or mental well-being were asked how long it had taken after starting the meditation program for the effects to become apparent to them. Of the 10 participants who responded, most indicated that it had been about 1 to 2 weeks before noticing changes, whereas a few had either noticed effects very quickly or after a longer period of about 3 weeks. Table 3 shows the number of participants reporting various types of positive impacts from use of the meditation apps.

## Discussion

### General Discussion

The aim of this study was to report MPN patients' (ie, naïve or nearly naïve meditators) perceptions of meditation and explore their experiences in the context of using a mobile phone for meditation after participation in an 8-week, consumer-based meditation app feasibility study. The qualitative data provide in-depth information that can be used (combined with the results

of our published feasibility study) [12] in the selection of an app for a future efficacy intervention in cancer patients. The information may also inform content and features for future meditation apps targeted at cancer patients.

Overall, the qualitative findings of this study indicate that mobile phone-guided meditation was very well accepted and liked among MPN patients, although most patients who experienced both expressed a greater liking for the *Calm* app over the *10% Happier* app. However, regardless of which app patients preferred, they felt that mobile phone meditation positively impacted physical and mental well-being, including fatigue, sleep quality, and their ability to manage stress and anxiety. Overwhelmingly, all patients would recommend meditation to other MPN patients; most reported likeliness of continuing to meditate, and a majority reported a likeliness to continue meditating with one of the consumer-based apps. This was despite the finding that more than half of the participants had negative preconceptions about meditation, partially because of the stigma surrounding it [30]. Therefore, future studies are warranted to develop and test the introduction and educational components of meditation apps to assure they are tailored for the specific populations' preconceptions about meditation.

After participating in the study, a majority of participants indicated that they had enjoyed using the meditation apps. As mentioned above, most expressed the view that around 10 min was a suitable length of time for meditation sessions, and this seemed to contribute to their enjoyment of the apps. There is little previous literature available to suggest the ideal dose or length of meditation, as studies have varied quite considerably in their prescription [31]. This is especially the case in hematological cancers, with no research being conducted to date in MPN patients, before our recent feasibility study [11,12]. Meditation interventions have shown effects with time spent in meditation ranging from 10 min to 2 hours and from 1 day a week to a daily practice [32-34]. In a feasibility study of 5-, 15-, and 30-min meditation sessions, the 15-min sessions were the most feasible to implement among health care professionals [35]. This falls in line with current practical recommendations, in which it is recommended that beginners begin by meditating between 10 and 30 min per session [36]. Therefore, it seems that consumer-based apps that offer 10-min daily meditations are in line with what is feasible and most practical, on the basis of the current literature, and this likely contributed to the participants' enjoyment of the length of meditations. However, some of the participants in this study expressed a preference for



different or increasing lengths of meditation, which suggests that both the length of meditations at the outset of an intervention and the meditation's extension over time might usefully be explored in future feasibility studies. In a recent study by Huberty et al [17] that investigated the feasibility of 12 weeks of Web-based, home-based yoga in MPN patients, participants who completed the intervention noted that the flexibility and convenience of being able to do yoga at home instead of going to a studio was one of the best features of a remote intervention. Cancer patients report barriers that make it difficult to participate in in-person interventions [16], and mobile phone-based meditation helps in addressing these issues, as participants can participate in meditation when they want and where they want. It is likely that the convenience and flexibility of mobile phone-based meditation contributed to its feasibility, with some participants in this study commenting on the flexibility of this approach, as noted earlier.

Of those participants who reported a preference for one app over the other, a majority (91%; 20/22) expressed a preference for the *Calm* app. There may be other unique features of the *Calm* app that made it more preferable compared with the *10% Happier* app. Despite a lack of research on meditation apps, there has been some research investigating the desired features of physical activity-based and, more broadly, health behavior change-based apps. This research suggests automatic tracking and ease of tracking activity and progress, as well as integrated features (eg, syncing with social media platforms and music apps), are desired and make apps more likely to be used [37,38]. Although both the *Calm* app and the *10% Happier* app track meditation progress for the users, the *Calm* app immediately displays the current streak of meditation days and offers the users to (1) share the daily quote on social media (ie, Instagram, Facebook) or via text, (2) see their profile of meditation statistics and progress (ie, number of meditations completed, longest streak of meditations completed, and total meditation min) and share with others (ie, social media, text, and email), (3) rate the session, and (4) give 30 days of *Calm*. In comparison, the *10% Happier* app displays the days of the last week spent in meditation, and if the users choose, they can also see the minutes of meditation and number of sessions, and then they can share their progress.

There is also little research investigating the features of meditation apps that are most desired or wanted by users. This is despite the over 300 mindfulness- or meditation-based mobile phone apps available across the Google Play Store and Apple's App Store [20,23]. Laurie et al [39] suggest that meditation apps should be designed so that (1) users can be encouraged to find a proper time and place to meditate regularly and (2) users can be encouraged to integrate the mobile phone app with other features on their phone, such as alarms and calendar notifications reminding them to meditate; in addition, meditation apps (3) offer users alternatives to meditating sitting still in the case that the user wants to engage in movement of some sort as well (eg, mindful movement, such as yoga or tai chi), and (4) the app itself is more interactive and less passive. There is still much to be learned about the use of mobile apps to deliver meditation and the way to cater the app to the individual. As discussed above, most of the participants in this study reported mental or

physical health benefits. This is not surprising, as mindfulness meditation has been shown to improve a range of cancer-related symptoms, including treatment fatigue, emotional distress, and sleep disturbances, to name a few [6-8]. Meditation may have improved mental health (eg, anxiety- and stress-related symptoms) through its calming effects on the autonomic nervous system and its ability to help improve attentional control and regulation of emotions [40-42]. Some of the other reported benefits by participants, including sleep and fatigue in particular, may also be related to one another, as some reported that they felt less fatigued, as they had better quality sleep. It is possible that meditation helped participants sleep better because of a reduction in sleep-interfering ruminating cognitive processes [6,8,43]. The improved sleep may have then led to participants feeling less tired throughout the following day. However, it is also possible that meditation targeted fatigue indirectly through another mechanism. Meditation has been shown to reduce inflammation, and inflammation is a key driver of MPN fatigue [44-46]. Participants who used the *Calm* app mentioned the use of both the Sleep Stories and the background music nature sounds to help them fall asleep. Sleep Stories on the *Calm* app comprise a narrator telling a story or ancient fable in a bedtime story format. The Sleep Stories are intended to be relaxing and soothing, thereby helping listeners fall asleep. The background nature sounds available on the *Calm* app range in style, from the sounds of running water and birds chirping to the sound of rain on leaves and thunder rumbling in the background. Research has demonstrated the beneficial effects of listening to nature sounds or music on the ability to fall asleep and on sleep quality in both cancer and noncancer populations [47-49]. In regard to the Sleep Stories helping participants fall asleep, there is no research specifically investigating the effects of Sleep Stories and their impact on sleep outcomes. However, there has been research conducted using bedroom story routines that have been associated with better sleep outcomes (eg, improved sleep quantity and quality) [50]. In this study, it is unknown whether study participants listened to the Sleep Stories as part of a nightly routine or on an as needed basis to help them fall asleep. Research is needed that examines the effects of *Calm's* Sleep Stories and whether stories by themselves help improve sleep outcomes or whether stories integrated into a nightly routine is more efficacious for sleep outcomes. In this study, exactly half (24/48) of the participants indicated that they had stuck to a regular meditation schedule over the duration of the study. However, the time of day in which participants chose to meditate varied. Most (14/24) indicated that they meditated at night, before going to sleep. Conversely, the other 10 reported that they preferred to meditate at any other time of the day, including the morning, afternoon, or early evening. In the study by Laurie et al [39] mentioned earlier, the *Headspace* users (n=16) also had varied patterns of use. It could be that most participants in this study meditated at night, as it was a way of helping them fall asleep. It does seem that having a routine-oriented approach to daily meditation is important, as participants in the *Headspace* study indicated that the toughest part of meditating regularly was identifying a routine time, sticking with that time, and then integrating that routine into their busy lifestyles. The authors [39] suggested that the design of meditation apps should have content that teaches users how to fit meditation into their

lifestyle. It may be that meditating at a specific time each day is associated with a higher likelihood of consistent meditation, but future research in this area is warranted to explore this further.

### Limitations

This study is not without limitations. First, participants recruited for this study were not blinded to the nature of the intervention being tested. Participants knew they were volunteering for a meditation intervention delivered via a mobile app. It is possible that this could have attracted interested participants who were more likely to find using the meditation apps enjoyable and likeable. Second, qualitative findings are from a convenience sample of participants who agreed to participate in a postintervention interview, derived from the larger sample that completed the study as a whole. The interview was not required of all study participants, and it is possible that this led to a biased sample of interviewees. In addition, as *Calm* and *10% Happier* offer other content besides meditation (ie, sleep stories, interviews with experts, and educational classes and courses) and as participants had autonomy to use other content on the app, it is possible that participants could have had slightly different interventions when compared with each other. However, this was also built into the nature of the feasibility

trial, and this partially encouraged participants to explore other features of the app. Future efficacy studies should aim to deliver a stricter intervention.

### Conclusions

On the basis of the findings of this study, more research is needed to better understand the effects of mobile phone meditation on MPN patients and, more broadly, on cancer patients as a whole. The qualitative findings of this study suggest that MPN patients enjoy mobile phone meditation and experience beneficial effects on their mental health, sleep, fatigue, and pain from using a meditation app, but they prefer the *Calm* app (as compared with the *10% Happier* app). In addition, patients identify with certain design features that make a mobile-based meditation app more appealing (eg, soothing sounds and backgrounds, integration with social media platforms, automatic tracking of progress, and user statistics). Future research is needed that investigates the efficacy of mobile phone-based meditation and further explores the optimization of meditation app design and features to enhance uptake among users. Furthermore, researchers should explore the specific types of meditation sessions and the specific features of the apps that were accessed to better guide recommendations for its users.

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### Conflicts of Interest

RM reports research support by Incyte, Celgene, CTI, Abbvie, and Genetech. In addition, RM acts as a consultant for Novartis, La Jolla, and Sierra Oncology. JH reports being the Director of Science at *Calm*; however, she was not working in this position at the time of this study taking place. The authors do not report any additional conflicts of interest.

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## Abbreviations

**MPN:** myeloproliferative neoplasm

**MPN-SAF TSS:** myeloproliferative neoplasm Symptom Assessment Form Total Symptom Score

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Original Paper

# Feasibility of a Mobile Phone App and Telephone Coaching Survivorship Care Planning Program Among Spanish-Speaking Breast Cancer Survivors

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## Abstract

**Background:** Spanish-speaking Latina breast cancer survivors experience disparities in knowledge of breast cancer survivorship care, psychosocial health, lifestyle risk factors, and symptoms compared with their white counterparts. Survivorship care planning programs (SCPPs) could help these women receive optimal follow-up care and manage their condition.

**Objective:** This study aimed to evaluate the feasibility, acceptability, and preliminary efficacy of a culturally and linguistically suitable SCPP called the Nuevo Amanecer (New Dawn) Survivorship Care Planning Program for Spanish-speaking breast cancer patients in public hospital settings, approaching the end of active treatment.

**Methods:** The 2-month intervention was delivered via a written bilingual survivorship care plan and booklet, Spanish-language mobile phone app with integrated activity tracker, and telephone coaching. This single-arm feasibility study used mixed methods to evaluate the intervention. Acceptability and feasibility were examined via tracking of implementation processes, debriefing interviews, and postintervention satisfaction surveys. Preliminary efficacy was assessed via baseline and 2-month interviews using structured surveys and pre- and postintervention average daily steps count based on activity tracker data. Primary outcomes were self-reported fatigue, health distress, knowledge of cancer survivorship care, and self-efficacy for managing cancer follow-up health care and self-care. Secondary outcomes were emotional well-being, depressive and somatic symptoms, and average daily steps.

**Results:** All women (n=23) were foreign-born with limited English proficiency; 13 (57%) had an elementary school education or less, 16 (70%) were of Mexican origin, and all had public health insurance. Coaching calls lasted on average 15 min each (SD 3.4). A total of 19 of 23 participants (83%) completed all 5 coaching calls. The majority (n=17; 81%) rated the overall quality of the app as “very good” or “excellent” (all rated it as at least “good”). Women checked their daily steps graph on the app between 4.2 to 5.9 times per week. Compared with baseline, postintervention fatigue (B=-.26; P=.02; Cohen d=0.4) and health distress levels (B=-.36; P=.01; Cohen d=0.3) were significantly lower and knowledge of recommended follow-up care and resources (B=.41; P=.03; Cohen d=0.5) and emotional well-being improved significantly (B=1.42; P=.02; Cohen d=0.3); self-efficacy for

managing cancer follow-up care did not change. Average daily steps increased significantly from 6157 to 7469 ( $B=1311.8$ ;  $P=.02$ ; Cohen  $d=0.5$ ).

**Conclusions:** We found preliminary evidence of program feasibility, acceptability, and efficacy, with significant 2-month improvements in fatigue, health distress, and emotional well-being and increased knowledge of recommended follow-up care and average daily steps. Tailored mobile phone and health coaching SCPPs could help to ensure equitable access to these services and improve symptoms and physical activity levels among Spanish-speaking Latina breast cancer survivors.

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## KEYWORDS

Hispanic Americans; cancer survivors; mobile apps; feasibility studies

## Introduction

### Background

Women with breast cancer are living longer, and the number of survivors is increasing as the US population ages. Recognizing the need to address the long-term needs of cancer survivors, in 2006, the Institute of Medicine recommended that all cancer patients receive a survivorship care plan (SCP) with a summary of their treatments, follow-up care plan, and information on potential late effects, self-care, and resources [1]. In 2016, the American College of Surgeons Committee on Cancer developed an accreditation standard requiring cancer care programs to provide SCPs to all nonmetastatic patients treated with curative intent with annual evaluation of these plans [2]. However, providing patients with SCPs is ineffective unless cancer patients understand and know how to use this information.

Survivorship care planning programs (SCPPs), to be distinguished from SCPs alone, are patient-centered activation interventions providing information on recommended health care and self-care following cancer treatment [1]. SCPPs typically help patients understand and follow recommended care regimens and encourage healthy lifestyles. SCPPs can meet patients' information needs [3], improve communication with clinicians, and improve well-being [4]. In addition, SCPPs need to address healthy lifestyles as most cancer survivors tend to be overweight or obese and have sedentary lifestyles [5-7], particularly Latinos, [8] and strong observational evidence links these risk factors with poorer survival among breast cancer survivors [9]. Physical activity interventions, in particular, improve symptoms and health-related quality of life [10-12] and reduce the risk of recurrence and death among breast cancer survivors [13]. However, clinicians rarely provide lifestyle counseling to cancer survivors despite evidence that oncologists' recommendations are effective among cancer survivors [14,15].

Non-white cancer survivors, in particular, face ongoing informational needs to address fear of recurrence and management of symptoms, late effects of treatments, and lifestyle changes [16]. Latina breast cancer survivors experience disparities in knowledge of breast cancer survivorship, psychosocial health, lifestyle risk factors, and symptoms after treatment compared with their white counterparts [17-21]. Spanish-speaking Latina breast cancer survivors, especially, report many unmet medical, psychosocial, and informational needs that affect negatively their self-efficacy for managing

survivorship [22-24]. SCPPs could help these women receive optimal care and manage their condition. Preliminary evidence suggests high acceptability of mobile health (mHealth) apps among Latino cancer patients because of a high need for Spanish-language information and support on disease and treatment effects [25].

### Objectives

The objectives of this mixed-methods study were to develop and evaluate the feasibility, acceptability, and preliminary efficacy of a culturally and linguistically suitable SCPP called the Nuevo Amanecer (New Dawn) Survivorship Care Planning Program for Spanish-speaking breast cancer patients in public hospital settings as they approach the end of active treatment. The intervention was delivered via a written SCP and booklet, mobile phone app, and telephone coaching calls and aimed to decrease fatigue and health distress and increase knowledge and self-efficacy for managing cancer survivorship and physical activity levels.

## Methods

We describe the intervention components and then methods for examining feasibility, acceptability, and preliminary efficacy.

### Intervention

The 2-month intervention comprised 4 components: (1) hard copy of an individualized bilingual SCP, (2) Spanish-language survivorship information booklet, (3) Spanish-language mobile app called trackC with integrated activity tracker (Fitbit Zip), and (4) 5 weekly health coaching telephone calls in Spanish to reinforce survivorship care concepts and positive health behaviors. Combined, these components were designed to provide a support system for women's cancer survivorship needs. On the basis of Social Cognitive Theory, the individually tailored intervention was designed to improve outcomes by building self-efficacy for managing cancer (managing stress and fatigue by walking, recognizing symptoms, securing follow-up services, and communicating with physicians), using self-regulation tools of self-monitoring, goal setting, and feedback [26].

### Written Spanish Language Survivorship Care Plan

We adapted the American Clinical Society of Oncology (ASCO) SCP template [27] for low-literacy, Spanish-speaking Latinas, simplifying the layout and translating it into Spanish. Adaptations were based on iterative review by a Latina psycho-oncologist, 2 oncologists, a bilingual oncology nurse,

and 3 Spanish-speaking breast cancer survivors. Participants signed a medical release form, and study personnel extracted the information from medical records to complete the SCP. Completed SCPs were reviewed by the project director and the patient's oncologist or oncology nurse and scanned into the patient's electronic health record. This written bilingual SCP was given to participants at the second home visit.

### **Spanish-Language Survivorship Information Booklet**

We selected the "ASCO Answers: Cancer Survivorship" guide because it was comprehensive, easy to understand, and available in English and Spanish [28]. The guide covers what to expect after active treatment, including psychological, physical, sexual, reproductive, financial, and work-related challenges.

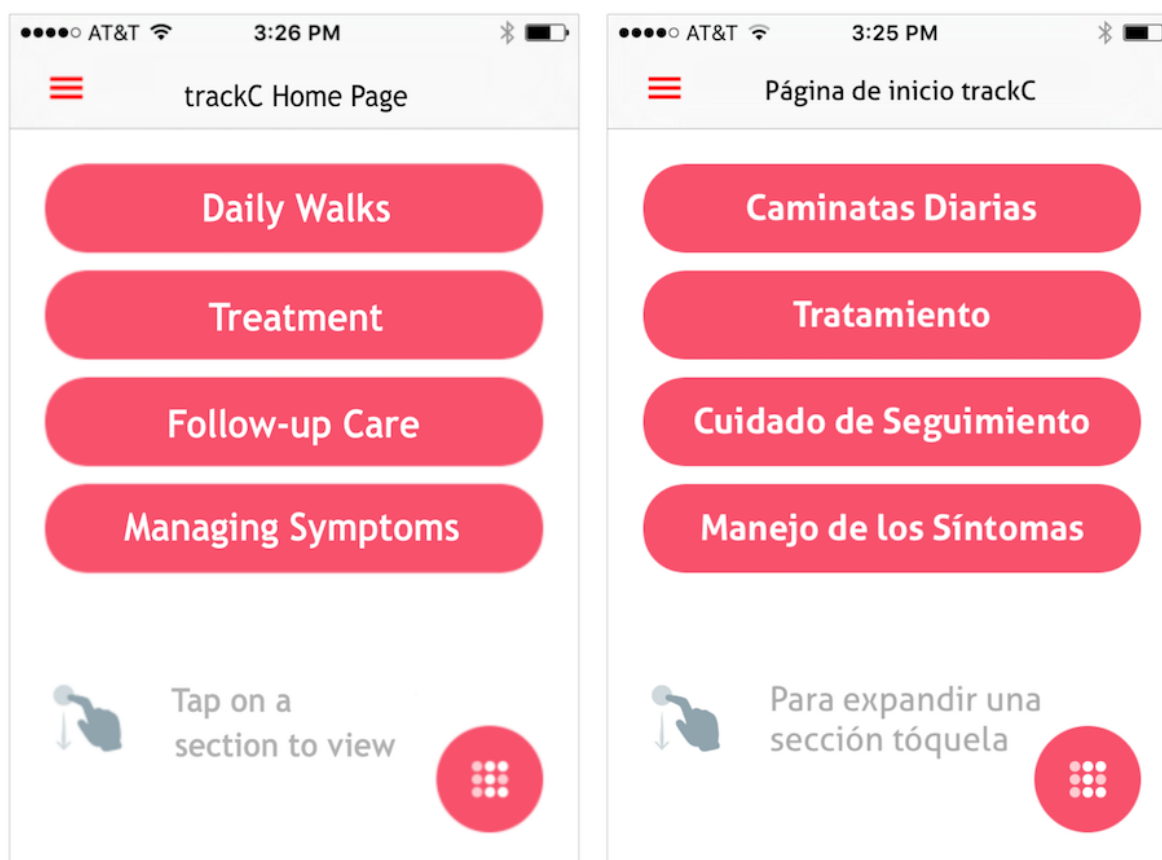
### **TrackC Mobile App With Integrated Activity Tracker**

The Spanish-language mobile app (trackC) was designed to contain women's breast cancer diagnostic and treatment history and provide information on potential side effects, healthy lifestyles, and survivorship resources. An activity tracker was integrated with the app to display progress toward a personalized daily steps goal. We selected the Fitbit Zip wireless activity tracker, henceforth referred to as activity tracker, based on cost, simplicity, and availability of an application programming

interface (API, for integrating the Fitbit with other software applications). The mobile app home page contained 4 section tabs (Figure 1): Daily walks (caminatas diarias), treatment (tratamiento), follow-up care (cuidado de seguimiento), and managing symptoms (manejo de los síntomas). Content was based on ASCO treatment guidelines at the time. We summarize each section briefly:

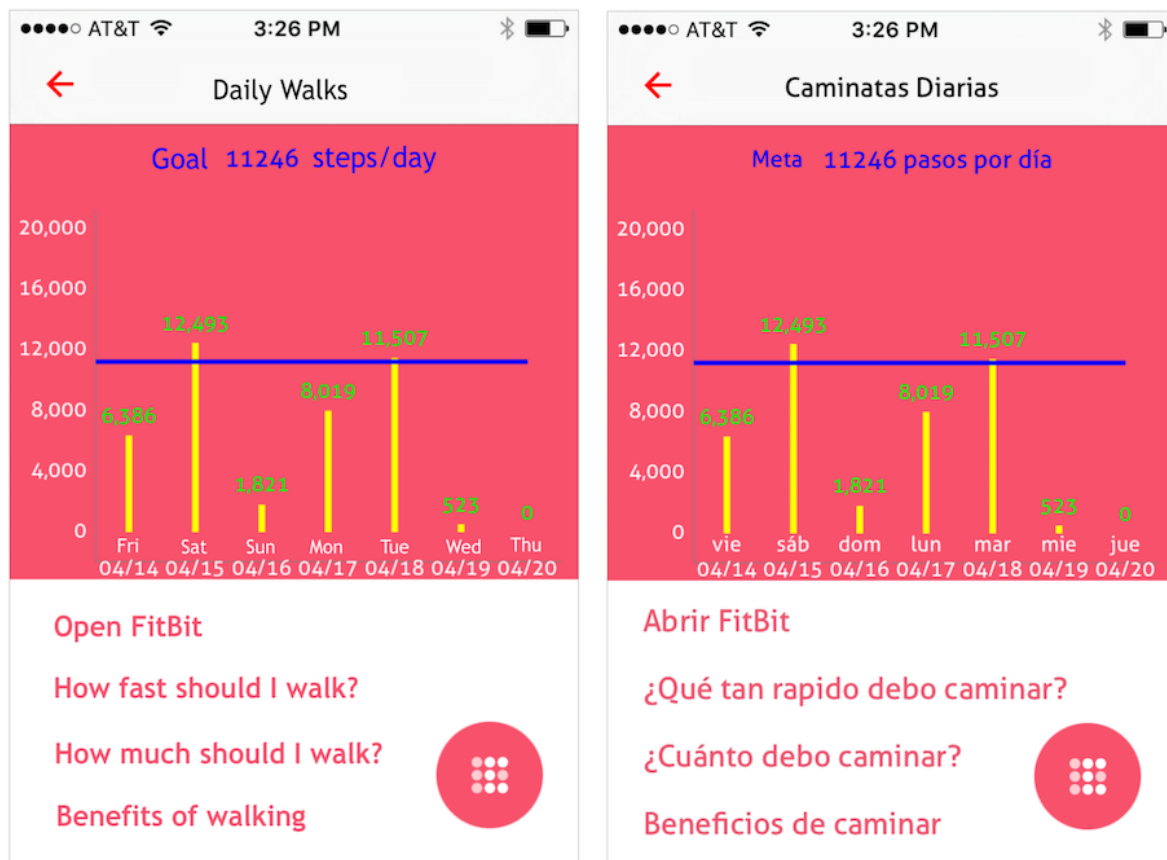
- Daily walks: information on walking and integrated activity tracker that could be synced with the app so that it displayed a history of daily steps and their average daily steps target (Figure 2).
- Treatment: screens for entering cancer diagnosis and treatment information that could be updated as needed and emailed to others, including clinicians.
- Follow-up care: general follow-up recommendations for women with noninvasive breast cancer; specific follow-up recommendations for those receiving radiation, tamoxifen, aromatase inhibitors, and women experiencing premature menopause; option to record pending medical appointments and receive reminder notifications.
- Managing symptoms: information on signs of recurrence, treatment side effects, daily exercise, nutrition, and cancer survivorship resources.

**Figure 1.** trackC mobile app home page: Caminatas Diarias (Daily Walks), Tratamiento (Treatment), Cuidado de Seguimiento (Follow-up Care), and Manejo de los Síntomas (Managing Symptoms).





**Figure 2.** Average daily steps graph of the trackC mobile app.



### Developing and Testing TrackC

In phases, we developed mock-ups, a detailed wire frame, and a prototype of the app employing user-centered testing [29] with iterative review and pretesting by 3 Spanish-speaking Latina breast cancer survivors; a Latina psycho-oncologist (breast cancer survivor); an oncologist serving ethnically diverse, low-income cancer patients; and 6 bilingual-bicultural study staff members. The prototype was developed in English and then translated into Spanish using rigorous forward translation and team reconciliation methods.

### Health Coaching Protocol

The coaching protocol was based on evidence-based motivational interviewing and health coaching techniques, which seek to actively engage patients in managing their health within their social contexts [30]. The health coach encouraged use of trackC, walking, reporting symptoms to clinicians, and calling clinicians to ask questions. Communication with clinicians was emphasized because of evidence that Latino patients often lack the confidence to report symptoms or ask questions, especially when the physician speaks a different language [31,32]. The health coach reinforced cancer survivorship information. The health coach was a bilingual-bicultural Latin American-trained internist with extensive health coaching experience. Coaching consisted of 5 weekly phone calls with the following structure: (1) review of progress toward daily steps goal and working

through any barriers, (2) daily steps goal setting for the coming week, and (3) information on a weekly health topic. The 5 health topics paralleled the trackC content and included: (1) walking and nutrition, (2) breast cancer follow-up care, (3) signs of recurrence, (4) treatment side effects, and (5) resources and review of content from the first 4 calls. The health coach used a manual, but tailored the content based on participants' needs.

### Study Design and Procedures

This single-arm feasibility study was conducted between February and June 2017, with women recruited from 2 public hospitals in Northern California. All study materials, including the app, were translated into Spanish using team translation and expert review and reconciliation by 6 bilingual-bicultural research staff. The study provided all participants with an iPhone and covered the costs of the data plan. Participants were compensated a total of \$60 for completing 2 assessments (baseline and post intervention). During the 2-month study, the same trained bilingual-bicultural research associate (RA) conducted 3 scheduled home visits: (1) enrollment visit (baseline assessment), (2) 1-week visit at the end of the activity tracker run-in period, and (3) final end-of-study visit (postintervention assessment). This protocol was approved by the University of California San Francisco and Contra Costa Regional Medical Center and Health Centers institutional review boards.

### **Eligibility and Recruitment**

Eligibility criteria consisted of: (1) self-reported Spanish-speaking Latina, (2) diagnosed with nonmetastatic breast cancer, and (3) within 1 year of termination of active treatment (except for hormonal therapy). Exclusion criteria included walking more than 30 min on 5 days per week or more. Using lists of potentially eligible participants provided by the hospital sites, we mailed them bilingual initial contact letters and postage-paid refusal postcards. A total of 2 weeks later, women who had not returned a refusal postcard were contacted in person or on the telephone by trained bilingual-bicultural RAs to conduct eligibility screening, ask about mobile phone usage, and schedule an appointment to visit the participant's home within 1 week.

### **Study Enrollment—Home Visit 1**

The RA conducted the enrollment visit (45-60 min) at the clinic site or the participant's home during which the study was explained in detail, written informed consent was obtained, participants signed a medical release form, and the baseline survey was completed. This marked the start of the 1-week run-in period. Women were provided with a masked activity tracker (hidden daily steps display) and instructions to wear it every day for a minimum of 10 hours per day and not to change their usual activity levels. This run-in period was used to establish participants' baseline average daily steps and personalized goal (average daily steps during run-in period + 2000 steps).

### **End of 1 Week Run-In Period—Home Visit 2**

In this 1-hour visit, participants received materials and verbal instructions on the use of the written SCP; survivorship booklet; iPhone and charger with trackC app installed; unmasked activity tracker (with visible daily steps and goal graph); and a step-by-step illustrated guide on how to use the iPhone, app, and activity tracker devices. The RA reviewed the SCP, survivorship booklet, device guide, and the individualized average daily steps goal to be achieved within 2 months. Women were instructed on synchronizing the tracker and mobile app at the end of every day to update the app's average daily steps graph. The RA helped participants enter diagnostic and treatment information from the written SCP into trackC.

### **End of Study—Home Visit 3**

At this visit, the RA conducted the final assessment and a brief satisfaction survey, synchronized the activity tracker with the Fitbit app to update the final daily steps data, and collected the mobile phone and charger. Participants were allowed to keep the tracker and encouraged to continue to maintain a daily exercise routine. Upon returning to the office, the RA logged in using the participant's study Fitbit account credentials and downloaded the Fitbit steps data to the study computer.

### **Acceptability and Feasibility Measures**

Acceptability and feasibility were examined via tracking of implementation processes evaluation indicators, debriefing interviews, and postintervention satisfaction surveys.

### **Implementation Processes**

An electronic database (REDCap) was developed to track usability issues [33]. This system contained data from multiple sources, including phone calls from participants, issues reported by the health coach, daily review of the mobile app back-end database, RA and project director tracking forms and notes, and timing of software updates for the activity tracker. Mobile app data were sent to the study's secure database via encrypted transmission. If the mobile phone or app lost connectivity, data were transmitted the subsequent time the app was connected to the internet.

### **Coaching Call Indicators**

The health coach recorded attendance and duration for the 5 calls. At every call, women were asked how many times in the past week they had synced their activity tracker with the trackC app and checked the app's average daily steps graph and if they had experienced any problems doing this. On calls 1 and 3, women were asked how difficult they found it to use the graph (5-point response scale was 0=not at all to 5=difficult). After every session, the health coach was asked to rate how much of the material she felt the participant had understood (5-point response scale was 0=none to 5=all).

### **Debriefing Interviews**

Semistructured debriefing interviews were conducted with a subset of participants to ask about their study experiences and suggestions for improvement. Selection of women was stratified to include those who had an iPhone versus other type of mobile phone or none, aged <50 versus ≥50 years, and from the 2 study sites. A trained bilingual-bicultural Latina interviewer (not the RA who conducted home visits) used an interview schedule that asked about their experience using the app (eg, what they did and did not like), ease of use, perceived usefulness for managing their cancer, and facilitating factors.

### **Satisfaction Survey**

A 5-min satisfaction survey was administered at the final home visit after downloading participants' activity tracker data for the study period and the final assessment. The survey asked them to rate the program's perceived quality, ease of use, and usefulness. Overall quality of the app was assessed using a 5-level response set of "poor," "fair," "good," "very good," or "excellent." Ease of use was assessed by asking about the overall difficulty of using the trackC app, syncing, and using the treatment summary, with response options of "not at all hard," "a little hard," "somewhat hard," "quite hard," or "very hard." Perceived usefulness was assessed by asking participants to rate how useful the app and health coach were for helping them gain a sense of control over their health and how useful the app was for keeping their cancer treatment information in one place and knowing about cancer symptoms and treatment side effects to monitor. Response options for the usefulness ratings were "not at all," "a little useful," "somewhat useful," "quite useful," or "very useful."

### **Efficacy of Intervention Measures**

To assess preliminary efficacy, we conducted baseline and 2-month interviews using structured surveys to examine changes

in symptoms, knowledge, and well-being. Changes in pre- and postintervention average daily steps count were assessed based on activity tracker data.

### Primary Outcomes

We measured 6 self-reported primary outcomes: 2 on symptoms, 3 on knowledge of cancer survivorship care, and 1 on self-efficacy for managing their cancer follow-up health care and self-care.

The 2 symptoms assessed were cancer-related fatigue and health distress. We adapted the *Patient-Reported Outcomes Measurement Information System (PROMIS) Cancer-Fatigue Scale*, which assesses the extent of fatigue and its impact on daily life over the past 7 days [34]. We dropped 1 item (“enough energy to exercise strenuously”) and added 2 items from the PROMIS Cancer Fatigue Short Form [35]: “felt tired when hadn’t done anything” and “limited social activities because of fatigue.” The final 7 items assess 4 aspects of severity (frequency that they felt tired, tired even when hadn’t done anything, extreme exhaustion, run out of energy) and 3 aspects of interference with daily life (frequency with which fatigue limited work, thinking clearly, taking bath or shower). To assess health distress, we selected 4 items from the Medical Outcomes Study Health Distress Scale [36] that asked how much of the time during the past month they felt discouraged, fearful, worried, or frustrated by their health problems. Response options for both fatigue and distress scales were as follows: “never,” “rarely,” “sometimes,” “often,” or “always.” Scale score were the mean of nonmissing items, with higher scores indicating greater fatigue effects (Cronbach alpha=.85) or health distress (Cronbach alpha=.91).

The 3 knowledge measures consisted of 2 global single item measures and 1 6-item scale. The 2 single items of global knowledge of survivorship care asked how true the following statements were for them: “you know what to expect now that your initial treatment has finished” and “you know how to take care of yourself after cancer.” The new scale assessed knowledge of follow-up care and ease of finding information. A sample item is “How true is the following statement for you: you know the possible side effects of your cancer treatment?” Response options for the 3 knowledge measures were 0=not at all true to 4=completely true. The scale was scored as the mean of nonmissing items with higher scores indicating greater knowledge (Cronbach alpha=.82).

A new 8-item self-efficacy for managing cancer care scale assessed confidence in ability to do what is needed to manage health care and health after cancer. A sample item is “How confident are you that you will be able to call your doctor if you have a question about a symptom that might be related to your cancer or treatment?” with response options of 0=not at all confident to 4=completely confident. The scale was scored as the mean of nonmissing items with higher scores indicating greater confidence (Cronbach alpha=.90). These new measures

assessing women’s sense of control over their survivorship care drew on published questionnaires [37,38].

### Secondary Outcomes

Secondary outcomes included emotional well-being, depressive and somatic symptoms, and average daily steps as recorded by the activity tracker.

Emotional well-being was assessed with the 6-item Emotional Well-Being Scale from the Functional Assessment of Cancer Treatment-General [39]. Scores range from 0 to 24, with higher scores indicating more well-being (Cronbach alpha=.77). We used the Patient Health Questionnaire 8-item version to assess depressive symptoms [40]. Scores range from 0 to 24, with higher scores indicating more depressive symptoms (Cronbach alpha=.64). We used the 6-item Brief Symptom Inventory Somatization Scale, which assesses the extent to which they were bothered by symptoms such as faintness and dizziness, pains in heart or chest, nausea, trouble getting their breath, numbness or tingling, and feeling weak [41]. Scores range from 0 to 4, with higher scores indicating more symptoms (Cronbach alpha=.76).

Baseline steps were calculated as the average daily steps during the 1-week run-in period (total steps divided by number of days) before the intervention start date. Postintervention steps were calculated as the average daily steps during the last week of the 2-month study period. Pre-post changes in average daily steps were calculated as the postintervention average daily steps minus the preintervention average daily steps.

### Analyses

Descriptive statistics were used to analyze sample characteristics and satisfaction survey responses. Debriefing interviews were transcribed verbatim in Spanish. A total of 3 bilingual-bicultural RAs independently performed content analyses of all transcripts, and discrepancies were resolved through team meetings. Linear mixed models were used to assess mean pre-post differences on primary and secondary outcomes; controlling for hospital site; and reporting unstandardized betas, *P* values, and Cohen *d* as an estimate of effect size.

## Results

### Demographic Characteristics

Of 100 women in the sampling frame, 23 enrolled in the study, 17 were ineligible, 17 could not be reached, 7 had incorrect contact information, 34 refused, and 2 were deceased. Mean age of participants was 55.8 years (SD 13.1), all were foreign-born and limited English proficient, most had an elementary school education or less (n=13), over half were of Mexican origin (n=16), and all had public health insurance (Table 1). About half (n=11) reported financial hardship in the past year, and most reported a comorbid chronic condition (n=17). The majority had breast conserving surgery (n=14) and both radiation and chemotherapy (n=15). Only 1 woman reported not owning a mobile phone.

**Table 1.** Descriptive characteristics of Spanish-speaking Latina breast cancer survivors participating in the Nuevo Amanecer (New Dawn) Survivorship Care Planning Program, Northern California (N=23).

Characteristics	Value
Age (years), mean (SD)	55.8 (13.1)
Years living in the United States, mean (SD)	20.1 (10)
<b>Educational attainment, n (%)</b>	
Elementary or less or did not attend school	13 (57)
More than elementary to high school graduate	5 (22)
Some college or college graduate	5 (22)
<b>National origin, n (%)</b>	
Mexican	16 (70)
Central American	6 (26)
South American	1 (4)
Married or living with a partner, n (%)	15 (65)
Employed full or part-time, n (%)	9 (39)
<b>Any financial hardship in past year, n (%)</b>	
Yes	11 (48)
No	11 (48)
Missing	1 (4)
<b>Type of health insurance, n (%)</b>	
MediCal (Medicaid in California)	19 (83)
MediCal and Medicare	4 (17)
Presence of comorbid chronic condition, n (%)	17 (74)
<b>Time since diagnosis, n (%)</b>	
1 year	8 (35)
2 years	3 (13)
3 years	5 (22)
4-5 years	7 (31)
<b>Type of breast cancer, n (%)</b>	
Invasive-ductal	15 (65)
Ductal carcinoma in situ	3 (13)
Other	5 (22)
<b>Surgery, n (%)</b>	
Breast conserving surgery	14 (61)
Mastectomy	8 (35)
None	1 (4)
<b>Treatment, n (%)</b>	
Adjuvant chemotherapy and radiation	9 (39)
Neo-adjuvant chemotherapy and radiation	6 (26)
Adjuvant chemotherapy only	1 (4)
Adjuvant radiation only	3 (13)
No treatment (no radiation nor chemotherapy)	4 (17)
<b>Self-rated health, n (%)</b>	
Very good or excellent	14 (61)

Characteristics	Value
Poor or fair or good	9 (39)
Own a mobile phone, n (%)	22 (96)
Use mobile phone to make calls at least once a week during the last month, n (%)	22 (100)
Send a short message service text message using mobile phone at least once a week during last month, n (%)	14 (64)
Use mobile phone to access the internet, n (%)	15 (68)

## Acceptability and Feasibility

### Implementation Processes

Nonscheduled home visits by the RA to all participants became necessary because participants requested help with the trackC app, activity tracker, or phone, or study staff noticed a lack of data transmission from trackC to the app backend database. A total of 63 nonscheduled visits occurred (mean=3 per participant, SD 1.9; range 1-7), during which the RA would troubleshoot technical and user issues and provide additional support and instruction. Most issues were related to technical (46 instances because of the app host site expiring, activity tracker software updates, or the app and tracker not syncing) or hardware-related problems (22 instances of activity tracker needing a new battery or the iPhone locking them out). Some were related to user issues (28 instances of forgetting to sync or how to do it, not knowing how to swipe out of an app section, or losing the activity tracker).

### Coaching Call Indicators

Coaching calls lasted on average 15 min each (SD 3.4). A total of 19 of 23 participants (83%) completed all 5 coaching calls, 1 woman completed 4 calls, 1 woman completed 1 call, and 2 women completed no calls. Number of times per week that women synced their activity tracker and app ranged from 4.4 to 5.7. Number of times per week that women checked their daily steps graph on the app ranged from 4.2 to 5.9. Ratings of the difficulty with using the daily steps graphs at call 1 and call 3 were almost identical, with most women (12 at call 1, 11 at call 2) rating it as not at all difficult. A total of 3 women reported vision problems interfered with reading the app screens. On the basis of the coach's ratings, the number of women understanding all of the material ranged from 17 (81%) for call 1 (daily steps and goal-setting) to 20 (100%) for call 3 (signs of recurrence).

### Debriefing Interviews

A total of 10 semistructured postintervention debriefing interviews were conducted (Table 2). Participants were aged 56 years on average, and most were from Mexico (Mexico=7, Guatemala=2, and Nicaragua=1). All participants reported elementary school completion or less. In general, participants reported positive attitudes toward the program and increased awareness of the importance of walking. Themes emerging from the interviews are described next.

### Perceived Usefulness of Intervention Components

Participants voiced appreciation for the trackC app information about their disease, treatments, side effects, and signs of recurrence, having felt misinformed about cancer survivorship before the study. All the women wanted the written SCP in addition to the app version. They reported feeling motivated and supported by the weekly check-ins with the health coach because she provided them with tailored, detailed, and credible information and support; helping them understand their disease, symptoms, and bodies; and achieve their walking goal. Participants valued the visual and auditory instant feedback provided by the activity tracker and app, for example, applause received after achieving their daily goal, helping them maintain a positive attitude toward walking.

### Perceived Ease of Use of Mobile App

Participants described varied experiences about the effort required to navigate and use the app. Users with mobile phone experience found the app easy to use. However, 4 of 10 participants with little or no mobile phone experience expressed that use of the app required more effort and support at the beginning of the study. Some participants reported difficulties because of poor literacy or poor eyesight. All women reported being satisfied with the app's interface, fonts, colors, and visuals.

### Perceived Benefits of Intervention

Informants reported positive outcomes related to walking. A total of 7 of 10 women reported enhanced physical health because of their participation in the study, including weight loss, improved digestion and bowel movements, and improved sleep. Participants also reported improved emotional well-being, that is, decreased stress and better mood.

### Social Norms

A total of 3 women felt a sense of accountability because they knew their steps were being monitored by themselves and others. Women reported that social support and encouragement from family members and neighbors pushed them to achieve their daily goal. Finally, several women expressed a shift from being extrinsically motivated by the app and coach to increase their walking to being intrinsically motivated because they wanted to do it for themselves.

**Table 2.** Themes from semistructured postintervention debriefing interviews of Spanish-speaking Latina breast cancer survivors participating in the Nuevo Amanecer (New Dawn) Survivorship Care Planning Program, Northern California (N=10).

Theme and subtheme	Illustrative quote
<b>Perceived usefulness of intervention components</b>	
App provided credible information about healthy lifestyles, side effects of treatments, and signs of recurrence.	“The app where you could find information you could trust. You see so many things on the internet, a home remedy, but nothing where you feel sure that what they are telling you is true.” (ID 9015)
Feedback provided by activity tracker and app graph of daily steps progress over time were motivating	“What motivated me to walk was wearing the pedometer to see how much I could walk in one day and that this was recorded (on the app) so that I would not forget how much I had walked the day before and the day before that.” (ID 8027)
Visual and auditory positive feedback from the app for steps taken (graphs of progress toward goal, cheering sounds) were motivating	“It seemed really important to me that when you met your goal, it was as if it (the applause) were saying, ‘Yay, you won!’ as if you had won a prize...and I liked it.” (ID 9015)
Health coach provided detailed, tailored information on their specific treatments and potential side effects and follow-up care and motivation and support for walking	“Yes, she (health coach) really helps you. She motivates you to walk, how to take care of yourself, your health, what you should discuss with your doctor in case you feel something. She (health coach) tells you, you need to be aware of your body and report anything unusual, like pain, to the doctor. She gives you great advice.” (ID 8010)
Goal setting provided motivation for walking	“Setting goals helped me focus...That helped me a lot. I used to not take my dogs for a walk, I would let them just run around here, but now I take my dogs for a walk so I can get more steps.” (ID 9001)
<b>Perceived ease of use of the mobile app</b>	
Ease of use varied with prior experience using mobile phone	“It was a little hard, but then I read the instructions that they had given me. I have a cell phone, but I only use it for emergencies and to communicate with my children. But my cell phone is very basic and the one I use here (for the study) is more advanced. But after a while, I got the hang of it.” (ID 9002)
Appearance, fonts, font size and colors—were satisfactory but a few suggested larger font and navigation buttons	“The button was in the corner and I would push it two or three times to get it to work. You need to have more room to be able to push the button.” (ID 8040)
<b>Perceived benefits of the intervention</b>	
More energy or less fatigue	“The walking is so good. I used to feel stressed, very tired, with no energy, and it all went away. At first, when I started walking, I would get tired, but now, I can’t believe it. After walking so much, I don’t get tired.” (ID 8010)
Improved emotional well-being (less stressed or more relaxed, distracted from her illness, better mood)	“For me, a lot changed an awful lot. Pushing myself to walk a little more, I <i>saw</i> the difference in how much better, physically and emotionally. It’s a different type of relaxation. You get home tired and you say, ‘I am going to go for a walk! But, then you start, and it relaxes you <i>so much</i> .’ ” (ID 9015)
Improved physical well-being (less pain, less constipation, lower blood pressure, weight loss, less leg swelling)	“Soon after I finished treatment, my legs would hurt a lot and get swollen. Once I started walking, it stopped. The pain and swelling went away. I weighed more and my legs hurt a lot and now my legs don’t hurt, I feel more motivated, and I have lost weight, and helped me feel less constipated.” (ID 9021)
Improved sleep quality and quantity	“Now that I walk more, I feel really good, relaxed, I even sleep. I used to spend the entire night; it would be 2 or 3 in the morning, tossing and turning I could not sleep. And now, (laughs) I feel that the more I walk, the more I relax, I get tired and I know that I sleep, whereas before, I never slept.” (ID 9016)
Improved body image	“I gained weight because of my cancer and treatment. At first it was hard for me to walk, but now I walk to work at least 3 days a week. Walking helped me feel better about my body. I even think I lost a little weight and I recently joined a gym.” (ID 9001)
Increased self-efficacy	“I liked it all because I can sync and see how much I walked, primarily the effort I make to walk, and to see what I am capable of, that is, to keep making progress...My motivation became to see the level of effort I had made throughout the day to walk to improve my own health. I would make the effort and sometimes I would not reach the goal I wanted to reach and I would not like that, but then I would think, ‘tomorrow I have to do it.’ ” (ID 8027)
<b>Social norms</b>	
Shift in extrinsic to intrinsic motivation	“I still continue to walk. I have it in my head now always, as if they left me with a goal. I know that I reached the goal, but that is what I feel now. That the reason I walk is for my health and now I eat healthy food. Just yesterday, I walked over 17,500 steps.” (ID 9016)

Theme and subtheme	Illustrative quote
Walking was a commitment that they made upon joining the study	“Yes, I liked it because I felt as if I had a commitment to walk that I had to deliver on.” (ID 8040)
Encouragement of family and friends	“I would get excited when I would open the app and the stars would come out. And my little boy would say, ‘Well, let’s go walk so we can see you meet your goal.’ And I would say, ‘Yes, let’s go!’ And my kids would say, ‘Mami, aren’t you going to walk today?’” and I would answer, ‘Yes, go get me the cell phone’ (laughs). They, too, were involved.” (ID 9002)

### Satisfaction Survey

A total of 21 of 23 women completed the final assessment, for a retention rate of 91%.

#### Overall Quality

The majority of the women (17/21; 81%) rated the overall quality of the app as very good or excellent (all rated it as at least “good”). The overall quality of the information received on how to use the trackC app was rated as very good or excellent by 16 women (76%); all rated it as at least good.

#### Ease of Use

Most women (15/21; 71%) rated the ease of syncing the trackC app and activity tracker as being not at all hard (Table 3). Fewer respondents reported it being not at all hard to use the treatment summary found in the trackC app (11/21; 52%).

#### Usefulness

Regarding their ratings of the usefulness of the SPCP for feeling more in control of their health, all except for 1 woman rated the health coaching calls as quite or very useful, and all women

reported the trackC app as quite or very useful. Almost all women (n=19) reported that the trackC app was quite or very useful for keeping their cancer treatment information in one place. Having information on trackC about cancer symptoms and side effects were both reported as being quite or very useful by 18 and 19 respondents.

### Efficacy of Intervention

#### Primary Outcomes

Regarding primary outcomes, compared with baseline, fatigue ( $B=-.26$ ;  $P=.02$ ; Cohen  $d=0.4$ ) and health distress levels ( $B=-.36$ ;  $P=.01$ ; Cohen  $d=0.3$ ) were significantly lower post intervention (Table 4). Women reported significantly greater knowledge of recommended follow-up care and resources after the intervention ( $B=.41$ ;  $P=.03$ ; Cohen  $d=0.5$ ); self-efficacy for managing cancer follow-up care did not change.

#### Secondary Outcomes

Of the secondary outcomes, emotional well-being improved significantly post intervention ( $B=1.42$ ;  $P=.02$ ; Cohen  $d=0.3$ ). Women’s average daily steps increased significantly from 6157 to 7469 ( $B=1311.8$ ;  $P=.02$ ; Cohen  $d=0.5$ ).

**Table 3.** Satisfaction survey of participants completing the Nuevo Amanecer (New Dawn) Survivorship Care Planning Program, Northern California (n=21).

Domain	Value, n (%)
<b>Program evaluation: quality</b>	
<b>How would you rate the overall quality of the trackC app?</b>	
Excellent	7 (33)
Very good	10 (48)
Good	4 (19)
<b>How would you rate the overall quality of the information you received on how to use the trackC app?</b>	
Excellent	4 (19)
Very good	12 (57)
Good	5 (24)
<b>Program evaluation: ease of use</b>	
<b>How hard was it to sync the trackC app and Fitbit?</b>	
Not at all hard	15 (71)
A little hard	6 (29)
<b>How hard was it for you to use the treatment summary found in the trackC app?</b>	
Not at all hard	11 (52)
A little hard	6 (29)
Somewhat hard	2 (10)
Very hard	1 (5)
Missing	1 (5)
<b>Program evaluation: usefulness</b>	
<b>How useful were the phone calls you had with the health coach for helping you feel as if you had more control over your health?</b>	
Somewhat useful	1 (5)
Quite useful	6 (29)
Very useful	14 (67)
<b>How useful was the trackC app for helping you feel as if you had more control over your health?</b>	
Quite useful	9 (43)
Very useful	12 (57)
<b>How useful was the trackC app for keeping your cancer treatment information in one place?</b>	
Somewhat useful	1 (5)
Quite useful	7 (33)
Very useful	12 (57)
Missing	1 (5)
<b>How useful was the trackC app for knowing what cancer symptoms to look out for?</b>	
Somewhat useful	1 (5)
Quite useful	8 (38)
Very useful	10 (48)
Missing	2 (10)
<b>How useful was the trackC app for knowing the side effects of the cancer treatments?</b>	
A little useful	2 (10)
Quite useful	9 (43)
Very useful	10 (48)



**Table 4.** Linear mixed model of pre-post changes in health outcomes and average daily steps count, controlling for site, Nuevo Amanecer (New Dawn) Survivorship Care Planning Program, Northern California (n=23).

Outcome measure	Preintervention, mean (SE) <sup>a</sup>	Postintervention, mean (SE) <sup>a</sup>	Unstandardized beta	P value	Cohen <i>d</i>
<b>Primary outcomes</b>					
Fatigue <sup>b</sup>	2.21 (0.17)	1.95 (0.13)	-.26	.02	0.4
Health distress <sup>c</sup>	2.32 (0.22)	1.96 (0.20)	-.36	.01	0.3
Know what to expect after initial treatment ends <sup>d</sup>	1.14 (0.26)	1.10 (0.31)	-.035	.92	0
Know how to take care of yourself after cancer <sup>e</sup>	1.93 (0.26)	1.74 (0.26)	-.194	.53	0.2
Know about needed follow-up care and resources <sup>f</sup>	2.04 (0.20)	2.45 (0.15)	.41	.03	0.5
Self-efficacy for managing cancer follow-up health care and self-care <sup>g</sup>	2.818 (0.19)	2.817 (0.16)	-.001	.99	0
<b>Secondary outcomes</b>					
Emotional well-being <sup>h</sup>	18.72 (0.89)	2.14 (0.83)	1.42	.02	0.3
Depressive symptoms <sup>i</sup>	4.68 (0.78)	5.30 (1.03)	.62	.43	0.2
Somatization <sup>j</sup>	0.71 (0.14)	.69 (0.14)	-.02	.83	0
Average daily steps <sup>k</sup>	6157 (526)	7469 (619)	1311.8	.02	0.5

<sup>a</sup>Controlling for study site and using intent-to-treat analysis (includes 2 participants who did not complete the postintervention survey).

<sup>b</sup>Adapted 7-item *Patient-Reported Outcomes Measurement Information System* Cancer Fatigue Scale-Short Form; possible range=1-5, high score=more fatigue.

<sup>c</sup>5-item subset of the Medical Outcomes Study Health Distress Scale; response options of 1=none of the time to 5=all of the time; possible range=1-5, high score=more health distress.

<sup>d</sup>New single item "How true is the following statement for you: you know what to expect now that your initial treatment has finished?" with response options of 0=not at all true to 4=completely true.

<sup>e</sup>New single item "How true is the following statement for you: you know how to take care of yourself after cancer?" with response options of 0=not at all true to 4=completely true.

<sup>f</sup>New 6-item knowledge of follow-up care scale with response options of 0=not at all true to 4=completely true; possible range=0-4, high score=greater knowledge.

<sup>g</sup>New 8-item self-efficacy for managing cancer care scale with response options of 0=not at all confident to 4=completely confident; possible range=0-4, high score=more confident.

<sup>h</sup>Emotional Well-being Scale of the Functional Assessment of Cancer Therapy-General; possible range=0-24, high score=better emotional well-being.

<sup>i</sup>Patient Health Questionnaire 8-item Scale; possible range=0-24, high score=more depressive symptoms.

<sup>j</sup>Brief Symptom Inventory Somatization Scale; possible range 0-4, high score=more symptoms.

<sup>k</sup>Calculated as the average daily steps during 1-week run-in period before intervention start and last week of the 2-month study period.

## Discussion

### Principal Findings

This study sought to develop and test the preliminary acceptability, feasibility, and efficacy of a multicomponent breast cancer SCPP designed for Spanish-speaking breast cancer survivors. The intervention consisted of a bilingual individualized written SCP, a Spanish language survivorship information booklet, a mobile app called trackC with an integrated activity tracker, and health coaching calls. We found preliminary support for the program, with significant 2-month improvements in fatigue, health distress, and emotional well-being and increased knowledge of recommended follow-up care and average daily steps.

Women reported checking their daily steps graph about 5 times per week and the majority indicated the app was not difficult

to use. The majority of women rated the quality of the app as "very good or excellent." Participants were motivated by the visual and auditory instant feedback provided by the activity tracker and app. In qualitative debriefing interviews, most women indicated that the app and coaching were useful for giving them a sense of control over their health, that the app provided a useful place for storing cancer and treatment information in one place, and that the SCPP resulted in increased physical activity, weight loss, and improved digestion and sleep. These results are consistent with similar studies that have demonstrated preliminary satisfaction with or interest in mobile phone app-based survivorship information among Latina [42] or non-white cancer survivors [43].

### Lessons Learned

Although women were receptive to the SCPP overall, we learned a number of lessons. First, women preferred receiving both the

mobile and written versions of their bilingual SCP, so a mobile app alone might not suffice. Further customization of SCPs to include breast cancer type-specific information, for example, hormone receptor status, would be helpful. We were able to provide this level of customization via the health coaching, but this level of customization of the app exceeded the budget of this pilot study but could be addressed in future studies. We did not anticipate the extent of technical issues involved in maintaining communication between the trackC app, the activity tracker API, and the database management API. Unanticipated updates in the APIs of the activity tracker or database management system necessitated unscheduled home visits to install these updates as participants often did not know how to do this. Women sometimes forgot to wear the activity tracker or sync their trackC app and tracker. A small number of women with limited mobile phone experience, low literacy, or vision impairments indicated some difficulty in navigating the app, thus, the app would need to be further tailored and tested to meet their needs. For some women with limited iPhone or mobile phone experience, individualized assistance in learning how to use apps was needed; for example, knowing how to swipe to advance to next screen required repeated reinforcement. Regarding the design of the app, in the future, we would enlarge and centrally position the button used to sync the app and activity tracker app as suggested by some women.

### Limitations

This study has limitations. As a feasibility study, we did not include a control group and the sample size was small. As the study was conducted in Northern California with mostly Mexican women, results may not generalize to other regions or Latino national origin groups. In addition, because this was a multicomponent intervention, we are not able to isolate the relative effects of each of the components. Finally, we

experienced a high refusal rate (60%), much higher than in our prior studies with women from the same population, so the final sample may not be representative of Spanish-speaking Latinas in our region. Notably, this study coincided with a period of increasing immigration raids and heightened fear in local Latino communities. In our study, one of the most common reasons women gave for refusing to participate was fear that they would be tracked by immigration officials via the Fitbit wearable device.

### Implications

Mobile phones offer promise as an excellent delivery mode among Latinos because of their widespread use of web-enabled phones to access the internet [25,44,45]. Mobile app interventions can be adapted for those with visual or auditory impairments and low literacy. Supplemental training and telephone health coaching can be provided to those with limited experience using mobile phones and to sustain levels of mobile app use. For many vulnerable populations, mHealth approaches alone may not suffice and more personal and intensive delivery modes will be needed. Some segments will prefer not to use mobile apps.

### Conclusions

Our pilot study results support investment in testing of smart phone and health coaching SCCPs among Spanish-speaking Latina breast cancer survivors. Additional research employing user-centered testing can identify the appropriate combinations of delivery modes and intensity of SCPPs for vulnerable subgroups of cancer survivors. Harnessing technology to address the needs of these groups ensures equitable access to its potential health benefits related to self-care and long-term cancer survivorship outcomes.

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### Conflicts of Interest

None declared.

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## Abbreviations

- API:** application programming interface
- ASCO:** American Clinical Society of Oncology
- mHealth:** mobile health
- PROMIS:** Patient-Reported Outcomes Measurement Information System
- RA:** research associate
- SCP:** survivorship care plan
- SCPP:** survivorship care planning program

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Original Paper

# Usefulness and Usability of a Personal Health Record and Survivorship Care Plan for Colorectal Cancer Survivors: Survey Study

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## Abstract

**Background:** As a result of improvements in cancer screening, treatment, and supportive care, nearly two-thirds of individuals diagnosed with colorectal cancer (CRC) live for 5 years after diagnosis. An ever-increasing population of CRC survivors creates a need for effective survivorship care to help manage and mitigate the impact of CRC and its treatment. Personal health records (PHRs) and survivorship care plans provide a means of supporting the long-term care of cancer survivors.

**Objective:** The purpose of this study is to characterize the usefulness of a CRC PHR and survivorship care plan and to describe the usability of these technologies in a population of CRC survivors. To our knowledge, this is the first study to assess a PHR and survivorship care plan specifically targeting CRC survivors.

**Methods:** Twenty-two patients with CRC were recruited from surgery clinics of an academic medical center and Veterans Affairs hospital in Indianapolis and provided access to an online Colorectal Cancer Survivor's Personal Health Record (CRCS-PHR). Survey data were collected to characterize the usefulness of the CRCS-PHR and describe its usability in a population of CRC survivors. CRC survivors were surveyed 6 months after being provided online access. Means and proportions were used to describe the usefulness and ease of using the CRC website. Open-ended questions were qualitatively coded using the constant comparative method.

**Results:** CRC survivors perceived features related to their health care (ie, summary of cancer treatment history, follow-up care schedule, description of side effects, and list of community resources) to be more useful than communication features (ie, creating online relationships with family members or caregivers, communicating with doctor, and secure messages). CRC survivors typically described utilizing traditional channels (eg, via telephone or in person) to communicate with their health care provider. Participants had overall positive perceptions with respect to ease of use and overall satisfaction. Major challenges experienced by participants included barriers to system log-in, lack of computer literacy or experience, and difficulty entering their patient information.

**Conclusions:** For CRC, survivors may find the greater value in a PHR's medical content than the communication functions, which they have available elsewhere. These findings regarding the usefulness and usability of a PHR for the management of CRC survivorship provide valuable insights into how best to tailor these technologies to patients' needs. These findings can inform future design and development of PHRs for purposes of both cancer and chronic disease management.

**KEYWORDS**

personal health record; colorectal cancer; survivorship; digital health; digital medicine

## Introduction

In 2016, almost 1.5 million people in the United States were expected to be living with a history of colorectal cancer (CRC) [1]. Although CRC continues to be the third most common cancer among both men and women [2], improvements in cancer screening, treatment, and supportive care have led to decreases in cancer mortality rates [3-5]. As a result, nearly two-thirds of the individuals diagnosed with CRC live for 5 years after diagnosis [6]. An ever-increasing population of CRC survivors creates a need for effective survivorship care to help manage and mitigate the impact of CRC and its treatment. Although the reduction in cancer mortality can be partially attributed to cancer treatments, many of the same treatments carry substantial risks and expose patients to adverse long-term or late effects [7]. In addition, up to 40% of CRC survivors develop recurrent disease [8], a fact that also leads to cancer worry among survivors [9]. Therefore, CRC survivorship care should include the identification and management of physical and psychological effects of CRC treatment, surveillance for cancer recurrence, and improved communication with providers [10] in order to fully address the needs of this population.

The use of health information technologies has been identified as a means of supporting the long-term care of cancer survivors [11]. However, there is a lack of evidence supporting patient-centered technologies including personal health records (PHRs) for this purpose [12,13]. This finding may result from little or no emphasis on the acceptability and usability of these technologies to the patients using them and the barriers to successful implementation of PHRs [14,15]. Common barriers to the optimal use of PHRs include the negative attitudes of patients (eg, perceiving self-tracking as extra work) and providers (eg, seeing the PHR as extra work), interface challenges, and privacy concerns [16]. Patient-centered technologies that undergo usability testing have been found to have greater success in overcoming barriers and achieving positive outcomes [16]. Existing literature on PHR usability in cancer care has been largely limited to breast cancer and shown positive results when these technologies are tailored to the needs of patients [17,18]. Jacobs and colleagues sought to understand the usability of a health management aid and found that effective use was associated with the development of a tool that was customizable, mobile, and integrated into the care of patients [18]. In the case of a clinical trial matching system embedded in a Web-based PHR, Atkinson and colleagues found that changing content and attending to usability issues improved breast cancer patients' satisfaction with the technology [17]. Thus, such approaches may prove valuable for improving the impact of PHRs for CRC survivors.

Although the literature on the use of cancer-specific PHRs focuses on breast cancer, the usefulness of these Web-based technologies may vary by the type of cancer. Every cancer type

is unique in its patient needs, treatment approach, and follow-up strategy. For example, a common side effect of breast cancer treatment is lymphedema, or swelling of the arms. Conversely, a common side effect of CRC is the need for an ostomy bag. Both represent challenges a patient must manage, which may be aided by an appropriately tailored technology. With respect to individual cancers, the usefulness of an online technology cannot be taken for granted. Importantly, the perspectives of the end user (patients with CRC) are vital to develop a patient-centered PHR tailored to the needs of the end user [19]. The purposes of this study are to characterize the usefulness of a CRC PHR and survivorship care plan and to describe the usability of this CRC PHR and survivorship care plan among a population of CRC survivors. To our knowledge, this is the first study to assess a PHR and survivorship care plan specifically targeting CRC survivors.

## Methods

### The Colorectal Cancer Survivor's Personal Health Record

The Colorectal Cancer Survivor's Personal Health Record (CRCS-PHR) was developed by adapting an open-source electronic health record (OpenMRS) [20] to deliver an online survivorship care plan to CRC survivors. The chosen features of the CRCS-PHR were drawn from an Institute of Medicine report, which recommended that every cancer patient receive a survivorship care plan summarizing information important to the individual's long-term care [21]. This information includes a treatment summary, type of cancer and treatments, and a survivorship care plan consisting of potential side effects of treatment and specific information about the recommended follow-up (surveillance) care. In the development of the CRCS-PHR, the guiding principle when making design decisions was patient centeredness; consistent with this approach, we created a technology to make medical information accessible to the patient, empower the patient to manage information through decision-support tools, and allow the patient to control whom the information would be shared with. [Table 1](#) summarizes the functions of the CRCS-PHR (see [Multimedia Appendix 1](#) for further details).

Users could create online relationships with their doctors of choice, whether primary care or specialist physicians. Participants did not need to download any particular software to use the Web-based CRCS-PHR. Given the information complexity of certain functions of the CRCS-PHR, the system had not yet been designed for the smaller visual window of mobile devices. CRC survivors were instructed how to use the CRCS-PHR at the time of study recruitment in person at health care clinics. Subsequently, both a video tutorial and detailed user's guide were available online to provide patients with directions on using the system.

**Table 1.** Description of functions of the Colorectal Cancer Survivor's Personal Health Record.

Function	Description
Treatment summary	Summarizes cancer diagnosis and treatment, including type of surgery and adjuvant therapy (chemotherapy or radiotherapy)
Side effects	Tailored compendium of possible side effects of treatment
Surveillance care	Surveillance tests are recommended to detect cancer recurrence. Tailored reminders about guideline-concordant surveillance care were delivered to the patient. A table also summarized tests completed and the next test due.
Community resources	Links to cancer survivor information resources and support groups.
Relationships	Patients identify role-based individuals (provider, caregiver) with whom to share the personal health record. Relationships are configurable to allow access to part or all components of the personal health record.
Journal	Patients enter <i>unstructured</i> information about their experience with cancer and treatment into a journal (using My Relationships; others with whom the journal is shared can write in-line comments)
Secure messaging	Enables patients to send and receive messages from individuals with whom they have created a relationship.

The Treatment Summary section of the CRCS-PHR provided patients with access to detailed information about their cancer type and treatment received, including surgery, radiation therapy (type and duration), and chemotherapy (type and duration), as well as any complications associated with treatment. Name and contact information were also provided regarding the primary care and treating physician of all modalities (surgeon, radiation oncologist, medical oncologist, and primary care physician). However, the Web-based system did not connect directly with their institutional or vendor-based electronic health record.

The research team obtained information presented in the Treatment Summary from the electronic health record and entered it into the CRCS-PHR on behalf of the patient at the time of enrollment into the study. Possible side effects were automatically communicated to the patient in the CRCS-PHR with an algorithm based on the treatment received (surgery, chemotherapy, or radiation therapy). Similarly, surveillance care reminders were automatically delivered to the patient with an algorithm based on cancer diagnosis (colon or rectal) and stage (I-III). Information about completed surveillance care and results were self-entered by the patient.

We conducted a feasibility study of the CRCS-PHR to determine the perceived usefulness and usability of the targeted PHR intervention among CRC survivors. The goal of the study was to gather information to guide the iterative development of the CRCS-PHR.

### Study Sample

Recruitment sites included surgery clinics at an academic medical center and Veterans Affairs (VA) hospital in Indianapolis. To be eligible, patients with CRC had to have received curative-intent therapy and be diagnosed with stage I-III CRC between 2 months and 30 months prior. Participants were excluded if they had metastatic disease or did not speak English. A total of 22 cancer survivors were recruited; a minimum of 20 patients was considered an appropriate recruitment goal for this feasibility study. Data were collected to better understand the needs and experience of patient end users prior to conducting a large, randomized controlled trial. All participants were surveyed 6 months after being provided online access to the CRCS-PHR in order to assess its usefulness, ease of use, and overall satisfaction.

## Measures

### Usefulness

Eleven items assessed the perceptions of usefulness patients associate with different elements of CRCS-PHR (scale of 1=not at all useful to 10=very useful): (1) Summary of my cancer treatment history, (2) Reviewing my follow-up care schedule, (3) Self-entering follow-up tests I had received, (4) Description of side effects, (5) List of community resources, (6) Creating and setting up relationships with family members or caregivers, (7) Communicating about my cancer diagnosis with family members or caregivers, (8) Creating and setting up a relationship with my doctor, (9) Communicating with my doctor, and (10) Sending mail messages through the cancer website.

### Ease of Use and Overall Satisfaction

Five items assessed ease of using the CRCS-PHR (scale of 1=poor to 10=excellent): (1) Ease of reading the site, (2) Overall organization of information of the site, (3) Ease of navigating the tabs on the site, (4) Ability to find information you want on the site, and (5) How fast the pages appear after you click on the link. Three items assessed the overall satisfaction with the CRCS-PHR features (scale of 1=not at all to 10=very well): (1) How well did the cancer website meet your expectations? (2) How likely are you to recommend this website to other cancer survivors? (3) Considering all of your experiences to date, how satisfied are you with the cancer website overall? In addition, three open-ended questions were used to assess barriers and facilitators to CRCS-PHR use: (1) What were barriers (or things that made it hard) for you to use the cancer Website? (2) What were facilitators (or things that made it easy) for you to use the cancer website? (3) What is the main improvement that you would suggest for the cancer Website?

### Ethics Approval

The study procedures and protocol were approved by the Indiana University-Purdue University Institutional Review Board for the protection of human subjects and the VA Research and Development Committee.

### Statistical Analysis

Means and proportions were used to describe the study population, usefulness of the CRCS-PHR features, and ease of using the CRCS-PHR. All quantitative analyses were conducted



using Stata statistical software (version 15.1; StataCorp, College Station, TX). Open-ended questions were qualitatively coded and analyzed by two coders working together using the constant comparative method [22]. This method involves reviewing the open-ended survey responses and then comparing them with the others that followed in order to identify themes based on the possible relations between each prior code [22]. Similar responses to each question were coded and grouped together.

## Results

### Overview

As seen in Table 2, slightly more than half of the participants were men (55%), which is comparable to the national CRC average of 52.7% [3]. The average age of participants with CRC in this study was 58 years, which is lower than the national average of approximately 70 years for patients with colon cancer and 63 years for patients with rectal cancer [3]. In addition, slightly more than half of the participants were college graduates or had a postgraduate degree (55%) or were employed full-time (54%). Most participants were married (68%) and earned at least US \$50,000 annually (64%).

**Table 2.** Characteristics of the study sample (N=22).

Characteristic	Value
Age (years), mean (SD)	58 (9.50)
<b>Gender, n (%)</b>	
Male	12 (55)
Female	10 (45)
<b>Marital status, n (%)</b>	
Married	15 (68)
Other	7 (32)
<b>Education, n (%)</b>	
Less than high school	0 (0)
High school or General Education Development	6 (27)
Some college or technical school	4 (18)
College graduate or postgraduate degree	12 (55)
<b>Income (US \$), n (%)</b>	
<30,000	6 (27)
30,000-50,000	2 (9)
>50,000	14 (64)

### Usefulness of Colorectal Cancer Survivor's Personal Health Record

CRC survivors' perceptions of the usefulness of the CRCS-PHR are presented in Table 3. On average, survivors tended to perceive features related to their care to be useful (measured on a 10-point Likert scale, where 1=not at all useful and 10=very useful). The highest-rated medical care features were found to be the summary of the patient's cancer treatment history and follow-up care schedule. However, self-entering follow-up tests was found to have slightly lower-than-average usefulness. In addition, overall, survivors tended to perceive features related to communication as not as useful.

### Ease of Use and Overall Satisfaction

Survivors' perceptions of the usability of the CRCS-PHR are listed in Table 3. With regard to the ease of using the CRCS-PHR, participants had overall positive perceptions. However, participants were neutral with respect to how fast the pages appear after you click on the link. With regard to satisfaction, participants were overall satisfied with their use of the CRCS-PHR.

Participants preferred to receive access to the CRCS-PHR when first diagnosed with CRC. With regard to the patients' view of when they would prefer access to the cancer website, a majority of patients preferred to receive access "Right away, when [they were] first diagnosed with colorectal cancer" (n=17, 77%).

**Table 3.** Perceived usefulness, ease of use, and satisfaction with Colorectal Cancer Survivor's Personal Health Record in the study sample (N=22).

Measures <sup>a</sup>	n (%)	Score, mean
<b>Usefulness of medical care features (1=not at all useful, 10=very useful)</b>		
Summary of my cancer treatment history	19 (86)	6.4
Reviewing my follow-up care schedule	20 (91)	6.3
Self-entering follow-up tests I had received	20 (91)	4.9
Description of side effects	20 (91)	5.7
List of community resources	19 (86)	5.4
<b>Usefulness of communication features (1=not at all useful, 10=very useful)</b>		
Creating and setting up relationships with family members or caregivers	20 (91)	4.1
Communicating about my cancer diagnosis with family members or caregivers	20 (91)	3.8
Creating and setting up a relationship with my doctor	20 (91)	4.6
Communicating with my doctor	20 (91)	4.6
Sending mail messages through the cancer website	20 (91)	4.3
<b>Ease of using the CRC<sup>b</sup> website (1=poor, 10=excellent)</b>		
Ease of reading the site	20 (91)	7.7
Overall organization of information of the site	20 (91)	7.1
Ease of navigating the tabs on the site	20 (91)	7.2
Ability to find information you want on the site	20 (91)	7.5
How fast the pages appear after you click on a link	20 (91)	4.8
<b>Satisfaction with the CRC website (1=not at all, 10=very well)</b>		
How well did the cancer website meet your expectations?	20 (91)	6.2
How likely are you to recommend this website to other cancer survivors?	21 (95)	7.6
Considering all of your experiences to date, how satisfied are you with the cancer website overall	20 (91)	6.3
<b>Preference of timing to receive access to the cancer website: If given the chance, when would you first like to have had access to this cancer website?</b>		
Right away, when I was first diagnosed with colorectal cancer	17 (77)	N/A <sup>c</sup>
Not right away, but before any treatment for cancer	2 (9)	N/A
After surgery, but before other treatments	1 (5)	N/A
During treatment (including radiation or chemotherapy)	0 (0)	N/A
After all treatment is completed (including radiation or chemotherapy)	1 (5)	N/A

<sup>a</sup>All responses to individual survey items were included. One respondent only answered the question "How likely are you to recommend this website to other cancer survivors?" and another respondent did not rate the usefulness of all medical care features.

<sup>b</sup>CRC: colorectal cancer.

<sup>c</sup>N/A: not applicable.

## Open-Ended Responses

Table 4 presents representative examples from the answers to open-ended questions that reflect recurrent themes within the qualitative data that were expressed by more than one participant. The major challenge experienced by participants was logging into the system. Other challenges included inexperience and lack of computer literacy as well as difficulty entering their patient information. Facilitators to use of the CRCS-PHR included a user-friendly interface and easy navigation.

Participants stated that the CRCS-PHR was most valuable with respect to its medical care functions; however, it would have been more useful earlier in their cancer journey. With respect to communication, participants typically described resorting to traditional means of communication with their health care provider (ie, in person or via telephone). Participants also expressed interest in communicating with other CRC survivors in online networks in order to have a support group of individuals who had similar experiences.

**Table 4.** Representative responses from the open-ended questions.

Theme	Excerpt
Barriers to use	<ul style="list-style-type: none"> <li>• Logging in - could use it at first and then couldn't use it</li> <li>• Getting password and making part of routine</li> <li>• Password - could not change it</li> <li>• Lack of computer skills</li> <li>• Inputting my own information because it was time-consuming</li> </ul>
Facilitators to use	<ul style="list-style-type: none"> <li>• Self-explanatory &amp; navigate tabs, very user friendly</li> <li>• Easy to understand and find information</li> <li>• Didn't have to think much (user friendly)</li> <li>• Easy to navigate</li> </ul>
Communication with providers	<ul style="list-style-type: none"> <li>• Rather talk in person</li> <li>• Easier to contact over phone</li> <li>• Lack of time &amp; rather talk in person</li> </ul>
Communication with family, caregivers, and friends	<ul style="list-style-type: none"> <li>• More of a private person</li> <li>• Private about medical information</li> <li>• Like to keep things private</li> </ul>
Communication with other CRC <sup>a</sup> survivors (suggested improvements)	<ul style="list-style-type: none"> <li>• More exchange to other cancer survivors</li> <li>• Website for specific cancers for others with same cancer to network</li> <li>• Highlight resources more with specific feature - CRC networking site</li> </ul>

<sup>a</sup>CRC: colorectal cancer.

## Discussion

### Principal Findings

We found divergence between the perceived usefulness of medical care functions compared to communication functions. Participants reported that the majority of medical care functions of the CRCS-PHR had better than average usefulness. This finding is consistent with a qualitative study of CRC patients and providers, which found that CRC patients wanted to have general and tumor-specific health information and be able to track the course of illness and treatment over time [19]. Conversely, participants found communication functions less useful. Although patients are interested in communicating with their providers electronically [23,24], older individuals are less likely to communicate online with a health care provider. Our qualitative, open-ended responses provided further insight into why participants might have given communication functions lower scores. Communication functions, from the patient perspective, may be better handled by other platforms such as via the telephone or other nonelectronic modes of communication.

Given that our participants reported limited experience using technology, they may resort to forms of communication with which they are more familiar when communicating with their health care provider. Several participants mentioned that it was easier to call their doctors than to communicate with them electronically. This is consistent with another study that found that patients viewed communication through the PHR as cumbersome and preferred contacting their provider's office directly [25]. Although another study found that patients viewed direct communication with their providers as a valuable feature, the lack of computer proficiency was cited as a barrier to using PHRs [26]. A previous review found that patients and providers

were more likely to find these functions useful if they perceived them to be more beneficial than the existing options [16]. Successful use is also dependent on the buy in from providers who assure their patients that this form of communication is meant to supplement the existing patient-provider relationship, not replace it. Factors limiting provider buy in include provider perceptions that the PHR will result in extra work being added to their current clinical responsibilities [16] as well as concerns that patients will perceive them as being permanently on call [19].

Divergence between the perceived usefulness of medical care and communication functions may also be explained by several other factors. Patients may view medical data as information that is uniquely held by health care providers. Consequently, an online portal that provides tools for patients to obtain this previously inaccessible information may be considered to have great value. Conversely, online tools that facilitate communication with family members or caregivers may provide a solution to an issue that patients do not perceive as a problem. Cancer survivors may also be more reluctant to communicate with their providers online than the general population due to the personal nature of their disease or heightened concerns about privacy.

Participants reported that they would have preferred to receive the intervention either when first diagnosed or before treatment; many perceived that they received the intervention too late to receive the full benefits. Previously, concerns have been expressed about information overload at the time of diagnosis and that patients may have a difficult time remembering or processing information initially shared due to stress. However, data from this study suggest that patients are receptive to receiving survivorship care plans earlier, which indicates that

they are aware of the importance of information about cancer follow-up, enabling them to plan ahead [27].

Participants reported mixed experiences with respect to the ease of use of the CRCS-PHR. Although participants overall responded favorably to the interface, several reported issues with logging into the system. Participants were assigned passwords and able to communicate with the research team to have their password changed. Feedback from participants suggests that allowing them to select their own password and change passwords in an automated manner may remove the obstacles to accessing the CRCS-PHR. Initial access to patient portals and login problems have been a commonly observed problem [28,29]. Additionally, survivors flagged issues related to the downloading time for the CRCS-PHR. Slow download speeds highlight another dimension of access, and rural populations may be especially vulnerable, living in communities that lack high-speed broadband access.

Participants expressed concern about the amount of information they needed to input into the CRCS-PHR such as information about provider visits and treatments. Although the literature suggests that patients can reliably enter information for systems, including easy-to-measure biometrics such as height, weight, and temperature, most patients are unable to reliably report specific laboratory values [30]. When implementing a cancer survivorship care plan, PHRs can be tethered to health care providers' electronic health record, so that medical information is automatically transferred from the electronic health record to the PHR. Such processes would both minimize patient data entry and improve data accuracy, making the CRCS-PHR platform more scalable.

Similar to other studies reporting limitations related to the use of PHRs [25,26,31,32], some participants acknowledged a lack of experience using computers. Providing participants with access to basic training on the use of computers when needed would facilitate the use of these technologies. Short training sessions have been found to reduce computer anxiety and increase computer interest and self-efficacy among older adults [33,34].

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Screenshots of the Colorectal Cancer Survivor's Personal Health Record (CRCS-PHR) user interface of specific features and functions.

[[PDF File \(Adobe PDF File\)](#), [1MB](#) - [cancer\\_v5i2e10692\\_app1.pdf](#) ]

## Limitations

Our study recruited clinic-based samples from academic and VA health care settings, and thus, our findings may not be fully generalizable to cancer survivors seen in other community health care settings. The population was largely Caucasian, and experiences may be different among other racial or ethnic groups. Further, the mean age of the population (58 years) was lower than the average age of CRC patients (70 years). The use of new technologies may be easier among relatively younger patients; however, as the digitally proficient population ages, the use of online technologies will become more widespread. In addition, the developers and evaluators were separate teams managed by a common leadership (DH, principal investigator), and this organizational structure may have biased the study findings in favor of the CRCS-PHR; however, our study measures and analyses were prespecified, thereby limiting the influence of any unconscious bias. Finally, the study's cross-sectional design did not allow us to ascertain whether the perceived usefulness or usability of the tool changed over time with continued use.

## Conclusions

Survivors highlighted potential opportunities for the PHR to provide additional value in supporting their cancer care. This report is the first published study on the usability and usefulness of a PHR for the management of CRC and provides valuable insight on tailoring these technologies to patients' experiences. For CRC, patients may find the greater value in a PHR's medical care content than its communication functions, which are available elsewhere. Despite concerns about information overload, patients clearly expressed a preference to receive their care plan closer to the time of diagnosis and before the onset of treatment rather than later in the cancer care continuum. Like providers, patients may find data entry burdensome. Tethering these technologies to existing electronic health records would reduce this burden. Taken together, these findings will inform future redesign and development of PHRs for the purpose of cancer and chronic disease management.

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## Abbreviations

**CRC:** colorectal cancer

**PHR:** personal health record

**CRCS-PHR:** Colorectal Cancer Survivor's Personal Health Record

**VA:** Veterans Affairs

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Original Paper

# Evaluation of a Technology-Based Survivor Care Plan for Breast Cancer Survivors: Pre-Post Pilot Study

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## Abstract

**Background:** As of 2016, almost 16 million individuals were cancer survivors, including over 3.5 million survivors of breast cancer. Because cancer survivors are living longer and have unique health care needs, the Institute of Medicine proposed a survivor care plan as a way to alleviate the many medical, emotional, and care coordination problems of survivors.

**Objective:** This pilot study for breast cancer survivors was undertaken to: (1) examine self-reported changes in knowledge, confidence, and activation from before receipt to after receipt of a survivor care plan; and (2) describe survivor preferences for, and satisfaction with, a technology-based survivor care plan.

**Methods:** A single group pretest-posttest design was used to study breast cancer survivors in an academic cancer center and a community cancer center during their medical visit after they completed chemotherapy. The intervention was a technology-based survivor care plan. Measures were taken before, immediately after, and 1 month after receipt of the survivor care plan.

**Results:** A total of 38 breast cancer survivors agreed to participate in the study. Compared to baseline levels before receipt of the survivor care plan, participants reported increased knowledge both immediately after its receipt at the academic center ( $P<.001$ ) and the community center ( $P<.001$ ) as well as one month later at the academic center ( $P=.002$ ) and the community center ( $P<.001$ ). Participants also reported increased confidence immediately following receipt of the survivor care plan at the academic center ( $P=.63$ ) and the community center ( $P=.003$ ) and one month later at both the academic center ( $P=.63$ ) and the community center ( $P<.001$ ). Activation was increased from baseline to post-survivor care plan at both the academic center ( $P=.05$ ) and community center ( $P<.001$ ) as well as from baseline to 1-month follow-up at the academic center ( $P=.56$ ) and the community center ( $P<.001$ ). Overall, community center participants had lower knowledge, confidence, and activation at baseline compared with academic center participants. Overall, 22/38 (58%) participants chose the fully functional electronic survivor care plan. However, 12/23 (52%) in the community center group chose the paper version compared to 4/15 (27%) in the academic center group. Satisfaction with the format (38/38 participants) and the content (37/38 participants) of the survivor care plan was high for both groups.

**Conclusions:** This study provides evidence that knowledge, confidence, and activation of survivors were associated with implementation of the survivor care plan. This research agrees with previous research showing that cancer survivors found the technology-based survivor care plan to be acceptable. More research is needed to determine the optimal approach to survivor care planning to ensure that all cancer survivors can benefit from it.

**KEYWORDS**

cancer survivor; care plan; technology; patient activation

## *Introduction*

As of 2016, almost 16 million individuals were cancer survivors, including over 3.5 million survivors of breast cancer [1]. Because cancer survivors are living longer and have unique health care needs, the Institute of Medicine proposed a survivor care plan to alleviate the many medical, emotional, and care coordination problems of survivors [2,3]. Implementation of the survivor care plan is resource-intensive, requiring time and personnel to create and communicate the plan to survivors and other stakeholders [4,5]. Given the many time demands on health care providers, it is imperative to document the benefits of the survivor care plan to survivors. However, several randomized controlled trials have failed to show the benefits of the survivor care plan in relieving survivor distress, improving satisfaction with care, or improving care coordination [6-8].

A small body of research has not demonstrated the efficacy of the survivor care plan (both paper and electronic documents) in influencing survivor-reported outcomes. Three randomized controlled trials of a survivor care plan paper document and in-person session showed no effect on: cancer-specific or general psychological distress, health-related quality of life, satisfaction, or continuity of care [6], cancer worries, depression, or impact of cancer [7], or the helpfulness of the materials [8]. A technology-generated survivor care plan delivered after surgery and updated during follow-up visits showed a difference in the amount of information received (in favor of the survivor care plan group) but no difference in satisfaction with the information or care [9]. The survivor care plan group also reported more symptoms, expressed more illness concerns, more emotional upset, and reported more contact with their primary care physician.

While it is possible that survivors derive limited benefit from the survivor care plan, an alternative possibility is that other patient-reported outcomes, such as knowledge or confidence, could be better indicators of efficacy. Correlational studies have shown a link between receipt of a survivor care plan and increased knowledge and confidence of survivors [9-12]. Further evidence has been provided by a small randomized trial (N=79) about survivor transition coaching compared to usual care, which showed a trend for higher self-efficacy (an indicator of confidence) in the coaching group [13]. Another small randomized trial comparing two survivor care plan interventions showed increased confidence in both groups [14]. In a single-group study, perceived knowledge increased after the survivor care plan visit [15]. This evidence suggests that knowledge and confidence should be evaluated further as outcomes by which the benefit of a survivor care plan for patients can be measured.

In the context of other chronic diseases, such as diabetes or cardiac disease management, researchers have identified the construct of patient activation, which is defined as the

knowledge, skill, and confidence of an individual to manage their disease [16-19]. Based on this construct, Hibbard developed a patient activation measure to document self-efficacy regarding health behaviors, internal health locus of control, and readiness for involvement in care [20,21]. A small study of a technology-based symptom care plan for neurotoxicity during cancer treatment showed a significant improvement in activation from before to after use of the care plan [22,23], suggesting that this outcome could be relevant after cancer treatment. Two other randomized trials showed mixed results: no effect [13] and increased activation after the survivor care plan visit [14]. Because a goal of the survivor care plan is to help survivors to transition from a passive patient role to an active survivor role and become more responsible for their own health care, it is possible that this measure could more precisely document the benefit of survivor care plan delivery.

To address the resource issues associated with the survivor care plan, recent efforts have been made to use technology to automate components of the survivor care plan. These efforts reflect a broader trend to use technology as a means of increasing quality of care and patient outcomes while decreasing burden on health care professionals in both cancer care and health care overall [24-26].

Another line of research has focused on the use of technology-based survivor care plans for personalized survivor care plan delivery. Researchers evaluated a prototype of a smart phone application in a small sample of survivors and providers in a hypothetical situation [27]. Both patients and providers rated the prototype as usable, portable, and accessible. A Web-based program was designed to generate a tailored survivor care plan by incorporating input from the electronic health record and directly from patients [28]. In a sample of 25 breast cancer survivors, self-reported confidence was high before and after receiving the survivor care plan; 70% were very satisfied with it, and usability ratings were high. At least 75% of oncology and primary care providers endorsed the program. Investigators evaluated a technology-based platform with two components, a symptom care plan and a survivor care plan, and found the symptom care component to be feasible, usable, and acceptable to breast cancer patients receiving neurotoxic chemotherapy [22,23]. In contrast, a randomized study comparing two Web-based survivor care plan tools (completed by the provider versus the survivor) showed low completion rates by both groups [29], suggesting that technology alone may not solve the problem of survivor care plan implementation.

In summary, previous research provides some evidence that self-reported survivor knowledge, confidence, and activation may be sensitive to receipt of a survivor care plan, either paper or electronic. However, further research is necessary to examine survivor-reported outcomes and survivor experience associated with use of a technology-based survivor care plan. In addition to evaluating changes in survivor-reported outcomes during the implementation of a technology-based survivor care plan, this



research describes preferences for and satisfaction with the technology and format in which the survivor care plan was delivered.

The objectives of this pilot study were to: (1) examine self-reported changes in knowledge, confidence, and activation from before to after receipt of an electronically generated survivor care plan by breast cancer survivors in an academic cancer clinic and a community cancer clinic; and (2) describe survivor preferences for and satisfaction with implementation of an electronic survivor care plan.

## Methods

### Data Collection

The Institutional Review Board approved the research and each participant provided informed consent. Eligible individuals were required to: have pathologically confirmed breast cancer, stages I-III; be over 18 years old; be completing a course of chemotherapy; and be able to understand and read English. Participants recruited from a National Cancer Institute–designated comprehensive academic cancer center and a community-based cancer center were enrolled at the follow-up medical visit after completion of chemotherapy. The study used a single-group pretest-posttest design. Participants completed surveys both before (see [Multimedia Appendix 1](#)) and after (see [Multimedia Appendix 2](#)) the medical visit and then one month later (see [Multimedia Appendix 3](#)) to document changes in knowledge, confidence, and activation as well as preference for, and satisfaction with, the technology-based survivor care plan.

The intervention consisted of a customized survivor care plan that was developed and delivered via the Carevive Survivor Care Planning system, a proprietary cloud-based system. This system uses clinical data input into a proprietary rules engine that automatically generates a draft care plan based on diagnosis, treatment regimen, current clinical practice guidelines, and nationally established quality metrics. The clinician can review, edit, and customize the plan prior to sign off and delivery to the survivor. The customized survivor care plan includes a treatment summary as well as a care plan describing recommended medical tests, appointments to schedule, and links to vetted resources and reading materials about survivor health concerns that are maintained and updated by the vendor. As a survivor's treatment and disease history progress, providers can input additional information to the planning system and the survivor care plan will be updated accordingly. This feature of the Carevive system decreases the work required of providers in creating survivor care plans. Rather than requiring providers to continuously keep track of recommendations to survivors and update them based on treatment progression, the Carevive system allows them to simply transfer information on treatment and disease progression from the electronic medical record into the Carevive program interface, and then review and sign off on the survivor care plan that is automatically generated. Ideally, the survivor care plan document is delivered to the individual electronically (via email or encrypted flash drive), thus enabling full use of active links to information; however, the survivor care plan document can also be printed and delivered in paper

form per the preference of the survivor. The most prominent difference in features between the electronic and paper versions of the survivor care plan is that the electronic version includes embedded links that allow survivors to directly and immediately access educational resources on their personal computers or mobile devices. Within the Carevive platform, data are maintained in a secure database with Health Insurance Portability and Accountability Act–compliant standards of privacy and security.

### Survivor-Reported Outcomes

We evaluated knowledge and confidence with scales created by the researchers to document changes in survivor-reported knowledge of care expectations and confidence about completing the necessary tasks related to the care plan. These scales were used to distinguish knowledge or information deficits and self-efficacy or skill-related gaps. Each scale contained seven items rated on a 4-point scale from strongly disagree to strongly agree. An example of a knowledge item was: "I know which medical tests need to be done over the next year and when to get them done." A confidence item was: "I am confident that I will get the medical tests done on time over the next year." Within each scale, items were summed, the total score for each scale ranged from 7 to 28, and higher scores indicated higher knowledge or confidence.

We also measured self-reported survivor activation. The activation survey is a 13-item scale measuring the degree to which individuals feel prepared to actively participate in self-management [20,21]. Items are measured on a 4-point Likert scale with a range of strongly agree to strongly disagree. Total raw scores ranged from 13-52 (lowest to highest activation). Psychometric evaluation in previous research has revealed strong reliability and validity [20]. In groups with chronic illnesses, higher activation scores predicted higher likelihoods of engagement in preventive health behaviors, of seeking out health information, of performing regular self-monitoring at home, and of lower health care utilization [17,19,30]. In addition to being a measurable construct, activation can be influenced by interventions, such as delivery of a survivor care plan, that focus on providing information and resources to guide action [30,31].

### Survivor Preference and Satisfaction

We examined survivor preferences for the fully functional electronic format of the survivor care plan with or without a paper document versus the paper document alone. We asked participants to rate their satisfaction with the chosen format on a 4-point scale from strongly agree to strongly disagree, as well as to rate the acceptability of the content (ie, ease of understanding, helpfulness of the information and resources, satisfaction with the experience, and recommendation to others) on a separate 4-point scale from strongly agree to strongly disagree.

### Statistical Analysis

Demographic characteristics of the subjects were summarized by means and SDs or counts and percentages, as appropriate, stratifying by site (academic or community center). We assessed differences between the sites with two-tailed *t* tests and Fisher's exact test.

To evaluate the changes in the survivor-reported outcomes, we fit linear mixed models using the MIXED Procedure (PROC MIXED) in SAS 9.4 (SAS Institute Inc, Cary, North Carolina). Fixed effects included site, time point, and a site by time point interaction; a random intercept was allowed for each subject. We considered several possible correlation structures to account for the repeated measures within subject, including unstructured, compound symmetry, and first-order autoregressive, with the final selection, compound symmetry, based on Akaike Information Criterion. Boxplots display the distribution of knowledge, confidence, and activation scores for the subjects at each time point and site. We also used Fisher's exact test to evaluate the association between preferred survivor care plan

format and available demographics characteristics. For all analyses, Cronbach alpha=.05.

## Results

### Demographics

A total of 38 breast cancer survivors agreed to participate in the study, 15 in the academic center and 23 in the community center group (Table 1). The sample was primarily non-Hispanic white and married or partnered, and about half had at least some college education. Overall, 7/15 academic center participants (46%) and 8/23 community center participants (30%) were working at the time of the study.

**Table 1.** Demographic characteristics by clinical setting.

Demographics	Academic Center (n=15)	Community Center (n=23)	P value
Age, mean (SD)	57.6 (12.8)	52.3 (12.8)	.22
<b>Race, n (%)</b>			<b>.64</b>
African American	4 (27)	3 (13)	
Caucasian	11 (73)	19 (83)	
Other	0 (0)	1 (4)	
<b>Ethnicity, n (%)</b>			<b>.14</b>
Non-Hispanic	15 (100)	19 (83)	
Hispanic	0 (0)	4 (17)	
<b>Marital Status, n (%)</b>			<b>.88</b>
Single	2 (13)	2 (9)	
Married or partnered	10 (67)	17 (74)	
Divorced, separated, widowed	3 (20)	4 (17)	
<b>Education, n (%)</b>			<b>.08</b>
High school, vocational/technical	3 (20)	11 (48)	
College (Associates/Bachelors)	8 (53)	11 (48)	
Advanced degree	4 (27)	1 (4)	
<b>Employment, n (%)</b>			<b>.76</b>
Work full/part-time	7 (47)	8 (35)	
Unemployed	0 (0)	1 (4)	
Retired	4 (27)	8 (35)	
Disabled	4 (27)	4 (17)	
Homemaker	0 (0)	2 (9)	

### Survivor-Reported Outcomes

Participants at both sites reported significant increases in knowledge from baseline to immediately after receipt of the survivor care plan and 1 month later (Table 2). At baseline, the community center group had lower knowledge levels than the academic center group (mean difference 2.5; 95% CI 0.0-4.9;  $P=.05$ ). Knowledge was similar between the sites immediately post-survivor care plan and 1 month later (Figure 1). Baseline confidence was also slightly lower in the community center compared to the academic center group (mean difference 2.0; 95% CI 0.1-4.0;  $P=.04$ ) (Table 2). Confidence scores of the

community center group increased from baseline to immediately and 1-month post-survivor care plan, and confidence levels of the academic center group did not significantly change (Figure 2). Like knowledge and confidence, community center participants had lower levels of activation at baseline compared to the academic center (mean difference 3.9; 95% CI 0.3-7.5;  $P=.04$ ) (Table 2). The activation score improved for the community center participants at the immediate, post, and 1-month time points relative to baseline. Academic center participants saw modest improvement at the immediately post-survivor care plan time point (change=2.2; 95% CI 0.0-4.5;

$P=.05$ ), but the 1-month activation scores were not significantly different from baseline (Figure 3).

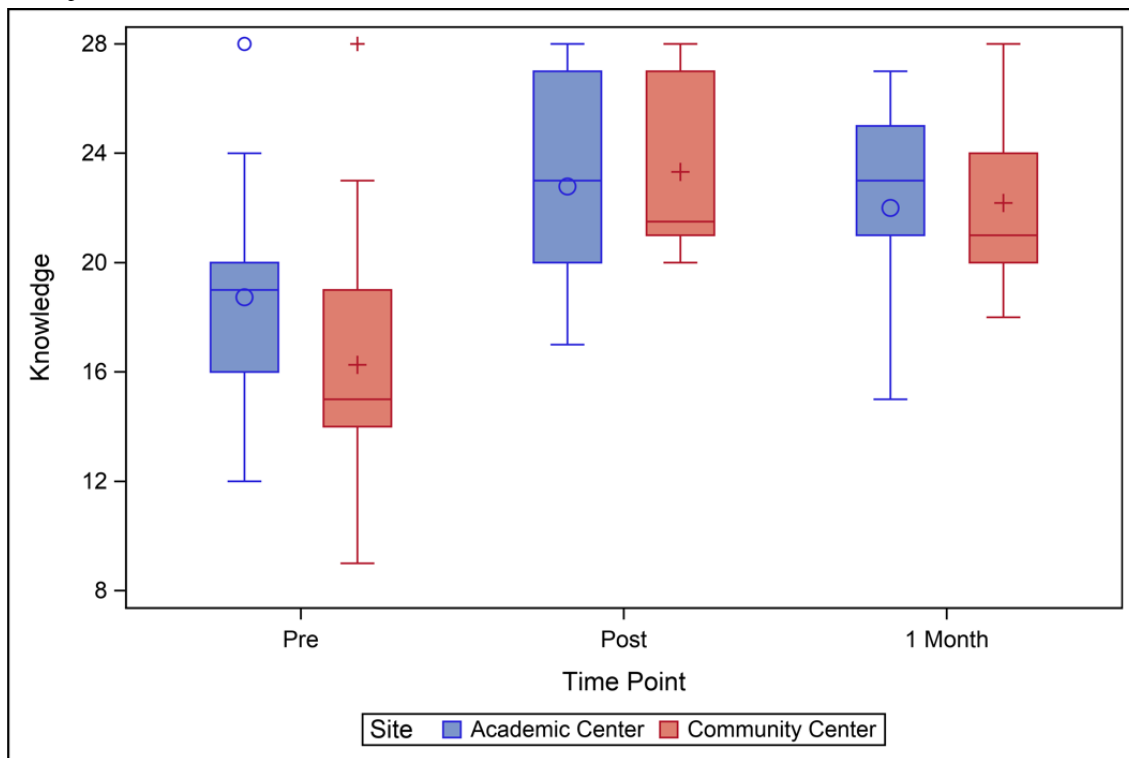
**Table 2.** Model-estimated least squares means for knowledge, confidence, and activation over time for each setting.

Categories	Academic center mean (95% CI)	Community center mean (95% CI)	Difference mean (95% CI)	<i>P</i> value
<b>Knowledge</b>				
Pre-SCP <sup>a</sup>	18.7 (16.8-20.7)	16.3 (14.7-17.8)	2.5 (0.0-4.9)	.05
Post-SCP	22.8 (20.8-24.8)	23.3 (21.7-24.9)	-0.4 (-3.0 to 2.1)	.73
1 month post-SCP	22.3 (20.3-24.3)	22.1 (20.6-23.7)	0.2 (-2.4 to 2.7)	.91
<b>Change from pre to post</b>	4.1 (2.0-6.2)	7.0 (5.3-8.7)	— <sup>b</sup>	—
<i>P</i> value	<.001	<.001	—	—
<b>Change from pre to 1 month</b>	3.6 (1.4)	5.9 (4.2-7.6)	—	—
<i>P</i> value	.002	<.001	—	—
<b>Confidence</b>				
Pre-SCP	23.6 (22.1-25.1)	21.6 (20.3-22.8)	2.0 (0.1-4.0)	.04
Post-SCP	24.0 (22.4-25.5)	23.3 (22.1-24.5)	0.7 (-1.3 to 2.6)	.51
1 month post-SCP	24.0 (22.4-25.6)	23.7 (22.5-24.9)	0.3 (-1.8 to 2.3)	.80
<b>Change from pre to post</b>	0.4 (-1.1 to 1.8)	1.7 (0.6-2.9)	—	—
<i>P</i> value	.63	—	—	—
<b>Change from pre to 1 month</b>	0.4 (-1.1 to 1.9)	2.1 (1.0-3.3)	—	—
<i>P</i> value	.63	—	—	—
<b>Activation</b>				
Pre-SCP	42.6 (39.8-45.4)	38.7 (36.5-41.0)	3.9 (0.3-7.5)	.04
Post-SCP	44.8 (42.0-47.7)	43.2 (40.9-45.4)	1.6 (-2.0 to 5.3)	.37
1 month post-SCP	43.3 (40.4-46.2)	43.1 (40.8-45.3)	0.2 (-3.5 to 3.9)	.91
<b>Change from pre to post</b>	2.2 (0.0-4.5)	4.4 (2.7-6.2)	—	—
<i>P</i> value	.05	<.001	—	—
<b>Change from pre to 1 month</b>	0.7 (-1.7 to 3.1)	4.3 (2.5-6.1)	—	—
<i>P</i> value	.56	<.001	—	—

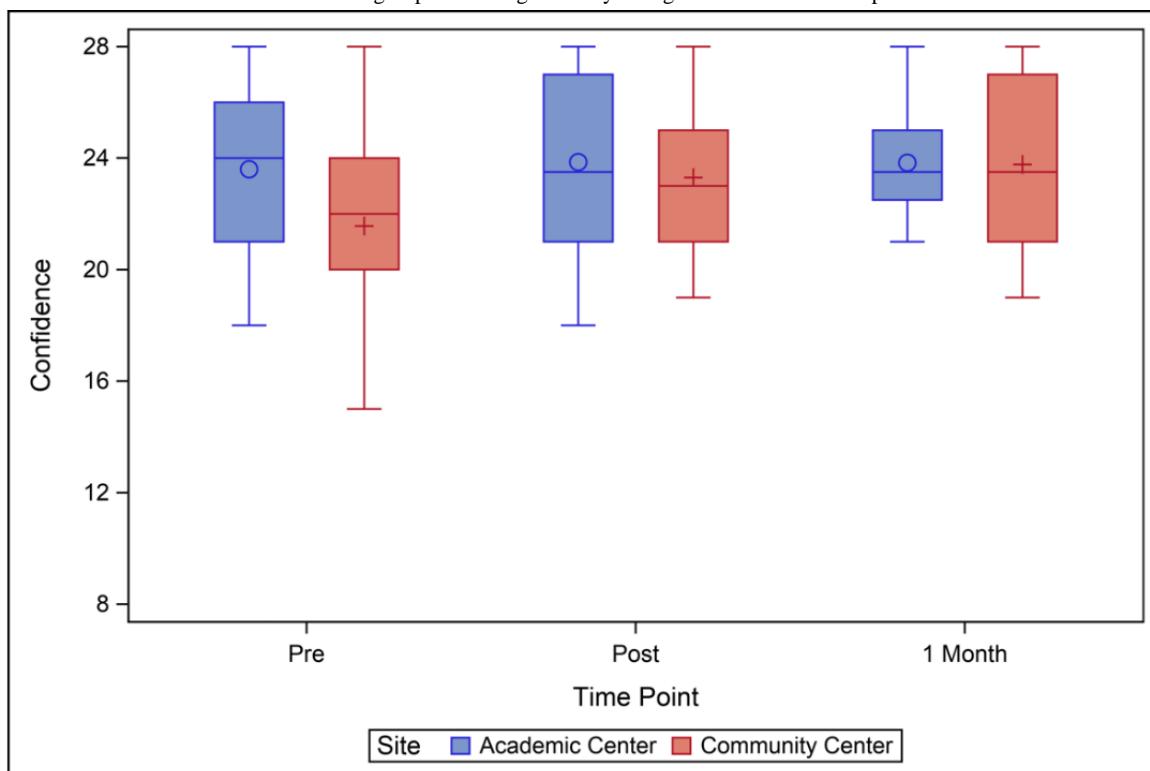
<sup>a</sup>SCP: survivor care plan.

<sup>b</sup>Not applicable.

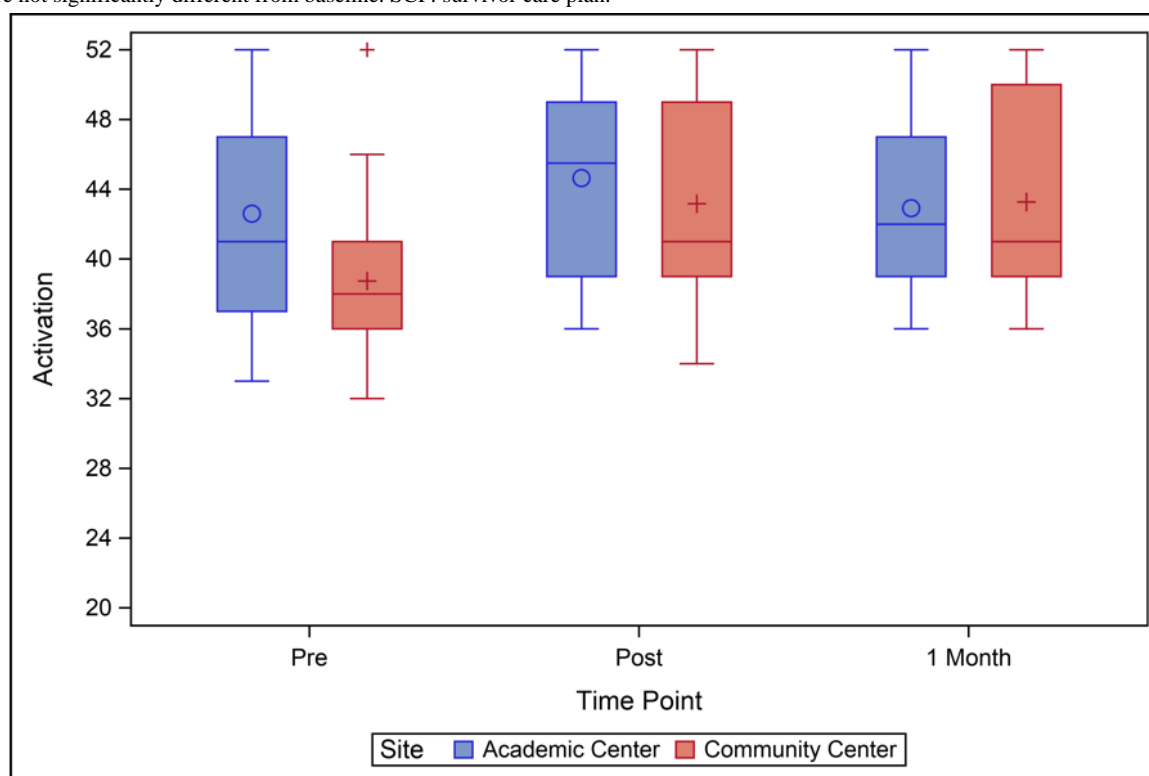
**Figure 1.** Knowledge levels of study participants before, immediately after, and one-month after SCP presentation. At baseline, the community center group had lower knowledge levels than the academic center group. Knowledge was similar between the sites immediately post-SCP and 1 month later. SCP: survivor care plan.



**Figure 2.** Confidence level before, immediately after, and one-month after SCP presentation. Confidence at baseline was slightly lower in the community center compared to the academic center. Confidence scores of the community center group increased from baseline to immediately and one month post-SCP; confidence levels of the academic center group did not significantly change. SCP: survivor care plan.



**Figure 3.** Activation levels before, immediately after, and one month after SCP presentation. Community center participants had lower levels of activation at baseline compared to the academic center. Activation score improved for community center participants at the immediate post and one-month time points relative to baseline. Academic center participants saw modest improvement at the immediately post time point, but the one-month activation scores were not significantly different from baseline. SCP: survivor care plan.



### Survivor Preference and Satisfaction

Overall, 22/38 (58%) of participants chose the fully functional electronic survivor care plan with or without a paper version (Table 3). It is noteworthy that 12 (52%) of the community center participants requested the paper version of the survivor care plan in comparison to 4 (27%) of the academic center participants. Survivor care plan format preference did not differ between sites with regard to age ( $P=.51$ ), employment status

(working versus not working,  $P=.86$ ), or education (high school versus college,  $P=.83$ ) (see Multimedia Appendix 4). All participants were satisfied with their chosen survivor care plan format, and almost all participants at both sites, regardless of chosen format, found the survivor care plan to be easy to understand, with useful information and resources. All but one participant agreed or strongly agreed that the experience was positive and that they would recommend the survivor care plan to other survivors.

**Table 3.** Preference for and acceptability of technology-based survivor care plan by clinical setting.

Categories	Academic center (n=15), n (%)	Community center (n=23), n (%)	P value
<b>SCP format</b>			<b>.16</b>
Flash drive	3 (20)	1 (4)	
Paper document	4 (27)	12 (52)	
Both flash drive and paper document	8 (53)	10 (43)	
<b>Format useful</b>			<b>.74</b>
Agree	7 (47)	13 (57)	
Strongly agree	8 (53)	10 (43)	
<b>Overall experience</b>			<b>.66</b>
Negative	1 (7)	0 (0)	
Positive	3 (20)	5 (22)	
Very positive	11 (73)	18 (78)	

## Discussion

The results of our examination of the efficacy of the survivor care plan show that participants reported positive changes in knowledge, confidence, and activation from before to after using the technology-based survivor care plan; this suggests that use of the survivor care plan could be responsible for these changes. While the positive change cannot be attributed definitively to the implementation of the survivor care plan, it suggests the need for a randomized controlled trial to test this hypothesis.

We noted that the confidence scores of the community center group increased from baseline to both subsequent time points, while the confidence levels of the academic center group did not significantly change. Community center activation scores were also improved at the immediately post-survivor care plan receipt time point as well as 1 month later, while activation scores at the academic center improved only modestly at the time point immediately post-survivor care plan receipt and at the 1-month time point were not significantly different from baseline. The differences in confidence and activation between the academic and community settings are difficult to explain.

Previous clinical trials evaluating survivor-level outcomes found no effect of survivor care plans on quality of life, mood disturbances, or satisfaction with care [6-8]. This research has identified alternative patient-reported outcomes that may more appropriately capture the variables likely to be influenced by a survivor care plan. Knowledge and confidence have both been identified in many theories as psychological variables that are likely to be involved in behavioral change [32-34]. Activation has also been identified in research on self-management of chronic diseases as an important indicator of readiness to take an active participatory role in one's health care [17]. Thus, despite a relatively small sample size, the fact that our exploratory study found positive changes in all three of these measures after survivor care plan implementation suggests that survivors may benefit from survivor care plan use, and also invites further investigation of survivor care plan efficacy.

The second goal of this research was to examine uptake of the fully functional electronic version of the survivor care plan versus the paper document only. In this sample, 22/38 (58%) participants chose the electronic survivor care plan, either by itself or in addition to the paper survivor care plan. A total of 34/38 (89%) participants chose the paper format, either by itself or in addition to the electronic survivor care plan. However, only 4/38 (11%) participants elected to receive just the flash drive, compared to 16 (42%) who elected to receive only paper. It could be argued that technology is not fully functional until a substantial majority choose the technology-based option. A platform that functions exclusively electronically thus runs the

risk of leaving behind patients who lack the skills to access it and deepening disparities that affect cancer patients and survivors.

Another feature of this study was the comparison between an academic and a community setting. Although we noted differences in survivor care plan format preference by treatment setting, the difference could not be attributed to age, education, or work status differences. However, we did not include any indicators of technological aptitude or savviness that could further explain the difference, such as frequency of interaction with an electronic interface or use of a smartphone. Regarding survivor care plan acceptability, our research agrees with past studies showing that cancer survivors have generally found technology-based survivor care plans acceptable [22,27,28]. Future research should evaluate the influence of technology literacy and aptitude on the choice of survivor care plan format in different clinical settings.

Our study sought to shed light on the potential for this novel electronic platform as a means of generating and delivering survivor care plans to breast cancer survivors. The fact that the survivor care plan examined in our study was offered in two formats strengthened our examination of survivor care plan efficacy by maximizing accessibility to participants. However, because the participants were offered the option of receiving their survivor care plan in both electronic and paper formats it limited our ability to draw conclusions regarding the electronic format, thus ultimately acting as a double-edged sword. Participants who selected both options were not queried about which of the formats they used, and their satisfaction with and perceived benefit from that format.

This pilot study had several additional limitations. First, it was not a randomized controlled trial, so the results are hypothesis-generating and not generalizable. Second, the sample size was small. A third limitation of this research was its lack of focus on clinician perceptions of this technology-based survivor care plan. A more robust evaluation of this intervention would require that all these limitations be addressed.

This research has contributed to the developing body of knowledge about the implementation of technology-based survivor care plans. The identification of patient-reported outcomes that are likely to be influenced by a survivor care plan intervention has been a barrier to success in previous research. It is possible that the outcomes measured in this research (knowledge, confidence, and activation) could be more appropriate indicators of efficacy for paper- or technology-based survivor care plans. Cancer survivors have attested to the acceptability of survivor care plans; however, challenges remain in fully implementing technology-based survivor care plans.

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Lerner, MD, whose commitment to this project in its earliest days was emblematic of his devotion to compassionate patient care in general and humanistic oncologic care in particular.

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### Conflicts of Interest

None declared.

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#### Multimedia Appendix 1

Survey administered to study patients in person before visit with medical oncologist in which SCP was given to them.

[[PDF File \(Adobe PDF File\), 47 KB - cancer\\_v5i2e12090\\_app1.pdf](#) ]

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#### Multimedia Appendix 2

Survey administered to study patients in person immediately after SCP was given to them by medical oncologist.

[[PDF File \(Adobe PDF File\), 50 KB - cancer\\_v5i2e12090\\_app2.pdf](#) ]

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#### Multimedia Appendix 3

Survey administered to study patients over the phone one month after receiving SCP.

[[PDF File \(Adobe PDF File\), 46 KB - cancer\\_v5i2e12090\\_app3.pdf](#) ]

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#### Multimedia Appendix 4

Supplemental Table 1: SCP format selection.

[[PDF File \(Adobe PDF File\), 89 KB - cancer\\_v5i2e12090\\_app4.pdf](#) ]

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Original Paper

# Providers' Perceptions of Parental Human Papillomavirus Vaccine Hesitancy: Cross-Sectional Study

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## Abstract

**Background:** Human papillomavirus (HPV) vaccine hesitancy among parents contributes to low vaccination coverage in adolescents. To improve health care provider communication and vaccine recommendation practices with hesitant parents, it is important to understand how providers perceive parental HPV vaccine hesitancy.

**Objective:** This study aimed to characterize perceived reasons for parental HPV vaccine hesitancy and identify factors associated with perceived parental hesitancy among providers at community-based pediatric clinics.

**Methods:** In 2018, providers in 23 community-based pediatric clinics in Tennessee were invited to complete a Web-based baseline survey as part of a larger quality improvement study focused on HPV vaccine uptake. These survey data were used for a cross-sectional, secondary data analysis. Scale scores ranging from 0 to 100 were calculated for provider self-efficacy (confidence in ability to recommend HPV vaccine), provider outcome expectations (expectations that recommendation will influence parents' decisions), and perceived parental HPV vaccine hesitancy. Provider confidence in HPV vaccine safety and effectiveness were categorized as high versus low. Clinic-level exposures examined were clinic size and rural-urban location. Descriptive analyses were used to characterize perceived parental barriers by provider type. Mixed-effects linear regression models were fit taking one exposure variable at a time, whereas controlling for provider type, age, gender, and race to identify provider- and clinic-level factors associated with perceived parental barriers to HPV vaccination.

**Results:** Of the 187 providers located in the 23 clinics, 137 completed the survey. The majority of physician providers were white and female, with a higher percentage of females among nurse practitioners (NPs) and physician assistants (PAs). The most common parental barriers to HPV vaccination perceived by providers were concerns about HPV vaccine safety (88%), child being too young (78%), low risk of HPV infection for child through sexual activity (70%), and mistrust in vaccines (59%). In adjusted mixed models, perceived parental HPV vaccine hesitancy was significantly associated with several provider-level factors: *self-efficacy* ( $P=.001$ ), *outcome expectations* ( $P<.001$ ), and *confidence in HPV vaccine safety* ( $P=.009$ ). No significant associations were observed between perceived parental HPV vaccine hesitancy and clinic-level factors *clinic size* nor *location*.

**Conclusions:** Researchers developing provider-focused interventions to reduce parental HPV vaccine hesitancy should consider addressing providers' self-efficacy, outcome expectations, and confidence in HPV vaccine safety to help providers communicate more effectively with HPV vaccine hesitant parents.

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**KEYWORDS**

neoplasms; papillomavirus infections; papillomavirus vaccines; primary prevention; health care provider; vaccine hesitancy; provider barriers to HPV vaccination

## Introduction

### Background

Human papillomavirus (HPV) vaccination coverage remains alarmingly low. In 2017, only 49% of adolescents aged 13 to 17 years in the United States completed the recommended doses of the HPV vaccine [1]. These rates fall short of the national goal of 80% coverage by 2020 for HPV vaccination of adolescents aged 13 to 17 years [2]. This warrants great concern as the effects of HPV infection remain high and many are at risk of HPV-associated cancers [3]. Parental vaccine hesitancy toward the HPV vaccine is a major contributor to low uptake of the vaccine and a growing public health problem [4-6]. According to a national survey, at least one-third of families are vaccine hesitant, meaning they delay or decline the HPV vaccine when initially recommended [7]. Therefore, understanding sources of parental hesitancy is important to develop strategies to address their concerns.

### Reasons for Parental Human Papillomavirus Vaccine Hesitancy

A growing literature has begun to explore HPV vaccine hesitancy among parents in recent years. Common reasons for HPV vaccine hesitancy reported by parents include misinformation, lack of or varying recommendation, lack of knowledge, and concerns about vaccine safety and side effects [7-10]. Improving the quality of provider-patient communication is a key strategy in addressing the needs of hesitant parents [11,12], given that routine provider recommendation is the most preferred approach among parents to influence HPV vaccine uptake [13,14]. A strong, high-quality recommendation should promote the importance of vaccine, demonstrate urgency, and emphasize cancer prevention [15]. According to a recent qualitative study with 43 HPV vaccine hesitant parents, providers with a persistent response in provider-patient interactions had higher rates of same-day vaccination compared with providers who did not [16]. A persistent response refers to a provider continuing discussion on the vaccine (ie, talking about its importance, providing a strong recommendation, and querying parental concerns on the vaccine) after a parent declines or expresses a desire to delay the vaccine [16].

### Parental Human Papillomavirus Vaccine Hesitancy and Provider and Clinic Level Factors

A previous study found a mismatch between provider and parental ratings of how much importance parents placed on HPV vaccine, with providers substantially overestimating the parental HPV vaccine hesitancy [17]. How providers perceive parental HPV vaccine hesitancy may determine their willingness to recommend the HPV vaccine, how they present the vaccine recommendation to parents, and how they respond when parents refuse the vaccine [18]. A few studies have explored what providers perceive as parents' reasons for HPV vaccine hesitancy and how these perceptions correlate with HPV

vaccination outcomes [19-21]. Thus, it is important to examine provider-level variation in how they perceive parental HPV vaccine hesitancy, given that many providers may not perceive parents' level of hesitancy accurately and that their perceptions of parental hesitancy are associated with provider-level variation in HPV vaccination rates. Yet, research to date has not identified the factors that influence provider perceptions of parental HPV vaccine hesitancy. These factors could be targets for interventions to improve provider communication and recommendation practices.

A previous study found that routine provider recommendations for the HPV vaccine were more likely to occur with providers who had a high confidence in their ability to recommend the vaccine and address parental concerns (ie, high context-specific self-efficacy). Providers with high expectations of their recommendations resulting in parents accepting the vaccine for their children (ie, high outcome expectations) were also more likely to recommend the HPV vaccine routinely [20]. Another study found that providers with lower confidence in HPV vaccine efficacy and safety had lower HPV vaccine uptake among their patients [19]. These provider characteristics could also influence their level of perceived parental HPV vaccine hesitancy. These characteristics should also be considered by provider type as: (1) a recent study suggests approximately one-half of initial recommendations are given by providers who are not physicians (Malo et al, in press; [15]); and (2) parent-provider interactions may influence perceptions of physician versus nonphysician providers differently and how they recommend the vaccine.

Clinic-level factors could also potentially affect perceived parental HPV vaccine hesitancy. For example, rural areas have lower HPV vaccination coverage compared with urban areas [1]. Lower coverage in rural areas could be due to a combination of fewer or weaker provider recommendations, greater parental hesitancy, or both. If providers in rural areas perceive greater parental HPV vaccine hesitancy compared with those practicing in urban areas, they may be less likely to recommend the vaccine strongly to avoid disagreements with parents. One study has shown that smaller clinics tend to provide a more *personal* experience and have fewer changes in doctors, whereas another indicated preventive service (eg, childhood immunizations) was more apt to be delivered by larger clinics [22]. Therefore, the size of clinic could influence the length and type of patient-provider interactions, which indirectly affects providers' perceived parental HPV vaccine hesitancy. However, no studies to our knowledge have identified specific factors that influence the types and level of parental HPV vaccine hesitancy that providers perceive and whether those factors vary by provider type.

The aim of this study was to characterize the reasons for and level of parental HPV vaccine hesitancy as perceived by pediatric providers at community-based, private pediatric clinics in Middle Tennessee. This study also aimed to identify

provider-level and clinic-level factors influencing perceived parental hesitancy according to providers. The research question was: “What are the provider and clinic characteristics associated with perceived parental hesitancy among pediatric providers within community-based pediatric clinics in Middle Tennessee, surveyed from January to March 2018?” We hypothesized that perceived HPV vaccine hesitancy would be higher among providers who have lower self-efficacy, lower outcome expectations, lower confidence in HPV vaccine safety, and lower confidence HPV vaccine effectiveness. We also hypothesized that perceived HPV vaccine hesitancy would be higher among clinics that were larger and are located in small towns that serve rural areas. Study findings can be used to develop interventions that assist providers in effectively engaging HPV vaccine hesitant parents to improve acceptance and vaccination outcomes.

## Methods

### Study Design and Data Source

This cross-sectional study used secondary data from 137 health care providers who provide care in 23 community-based pediatric clinics in Middle Tennessee. These providers are a part of an ongoing quality improvement parent study designed to compare the clinical effectiveness and cost effectiveness of 2 approaches to delivering quality improvement coaching focused on HPV vaccination, namely, Web-based coaching versus in-person coaching. As part of that parent study, providers completed a baseline survey that was collected from January to March 2018. This survey asked the providers questions related to HPV vaccine uptake in their clinics, their perceptions and attitudes related to HPV vaccine (eg, perceived barriers, self-efficacy, and outcome expectations), and demographic characteristics of providers. Clinic location (rural/urban) was determined based on the clinic address and clinic size was reported by the clinic. For this study, we analyzed data from the baseline provider survey data. This study was approved by Meharry Medical College and Vanderbilt University Institutional Review Boards.

### Study Population

The population was composed of providers from 23 private, community-based pediatric practices located across the Middle Tennessee Region that were members of Cumberland Pediatric Foundation (CPF). As a nonprofit organization, CPF applies scientific, charitable, and educational approaches to improve health care services for children. The foundation currently serves approximately 700 physicians, 70 practices, and 40 counties [23]. Practices were recruited for the parent study at events held by CPF or face-to-face by the research team. After practices made a practice-level decision to be in the trial, the providers were asked to take part in the survey. Providers included pediatricians, NPs, and PAs. The study inclusion criteria included all providers at each clinic, male or female, as they all provide HPV vaccines. None of the providers in the study clinics were excluded.

## Independent Variables

### Self-Efficacy

Adapted from McRee et al (2015) [20], the self-efficacy measure assessed providers' perceived confidence in their ability to recommend HPV vaccine and address parents' concerns. It was composed of 6 items using a 5-point Likert scale based on the level of agreement (ie, strongly disagree to strongly agree). Example items included “I was confident I could explain the benefits of HPV vaccination to parents” and “I was confident I could overcome parental concerns about HPV vaccine safety.” Before the analysis, the scores of the items responses were recoded using a range of 0 to 100 with 0=strongly disagree, 25=disagree, 50=neutral, 75=agree, and 100=strongly agree, so that there would be a comparable numerical range across all the scales for ease of interpretation (ie, standardization of the variables), given that the outcome variable was measured on a 4-point scale. Higher scores indicated greater levels of self-efficacy. McRee et al [20] developed the items using cognitive interviews with health care providers but did not report on psychometric properties of the scale. As there were no other validated measures for self-efficacy, we used this measure. In our sample, the self-efficacy scale demonstrated good internal consistency with Cronbach alpha=.79.

### Outcome Expectations

The outcome expectations measure, adapted from McRee et al (2015) [20], assessed providers' expectations for whether their parental discussions lead to vaccination. It was composed of 4-items using a 5-point Likert scale based on the level of agreement with specific statements (ie, strongly disagree to strongly agree). “I was usually able to convince hesitant parents to get the HPV vaccine” and “When parents wished to delay or refuse HPV vaccination, there was not much I could say to change their minds” were example items. Before the analysis, a negatively worded item was reverse coded so that all responses went in the same direction, and the scores of the item responses were recoded using a range of 0 to 100 with 0=strongly disagree, 25=disagree, 50=neutral, 75=agree, and 100=strongly agree. Higher scores indicated that providers had greater expectations that their parental discussions would lead to vaccination. As with the self-efficacy scale, these items were developed using cognitive interviews, but the authors did not report on the psychometric properties [20], and we chose this measure because there were no other validated measures for outcome expectations. In our sample, the outcome expectations scale demonstrated acceptable internal consistency with Cronbach alpha=.65.

### Confidence in Human Papillomavirus Vaccine Safety

Confidence in the HPV vaccine safety was measured at the provider level using a single ordinal item created by the research team asking: “Last year, how confident were you personally in the safety of the HPV vaccine for preventing cancer?” Response options were on a 5-point Likert scale ranging from very low to very high, and, before the analysis, the item responses were recoded using a range of 0 to 100 (0=very low, 25=somewhat low, 50=neutral or not sure, 75=high, and 100=very high). Higher scores indicated greater levels of

confidence in the HPV vaccine safety. For a multivariate analysis, the variable was dichotomized to compare very high with other categories.

### ***Confidence of Human Papillomavirus Vaccine Effectiveness***

This was measured at the provider level with a single ordinal item created by the research team that asked: "Last year, how confident were you personally in the effectiveness of HPV vaccine for preventing cancer?" Responses on a 5-point Likert scale ranged from very low to very high, and the scores were recoded using a range of 0 to 100 with 0=very low, 25=somewhat low, 50=neutral or not sure, 75=high, and 100=very high, as with the other scales. Higher scores mean greater levels of confidence in HPV vaccine effectiveness. This variable was dichotomized to compare very high with other categories for multivariate analysis.

### ***Size of Clinic***

This is a continuous variable at the clinic level, which represents the total number of providers, as reported by each clinic. Providers included physicians, NPs, and PAs in each clinic.

### ***Location of Clinic***

In total, 2 categorical variables at the clinic level were categorized based on the address of each clinic and 2 different US Census Bureau designations that reflect degree of urbanization. A metropolitan statistical area (MSA) is a geographic area that is associated with a least one urbanized area that has a population of at least 50,000 [24]. Non-MSAs are all areas outside of the designated MSAs. In addition, the US Census Bureau also defines 2 types of urban areas, which represent a densely settled group of Census tracts with a population meeting one of the following criteria: (1) 50,000 or more (urbanized area) or (2) at least 2500 and less than 50,000 (urbanized cluster) [24]. Each clinic was assigned values for the 2 separate variables based on the physical address as follows: (1) MSA versus non-MSA and (2) town/rural area (urbanized cluster) versus city (urbanized area).

## **Outcome**

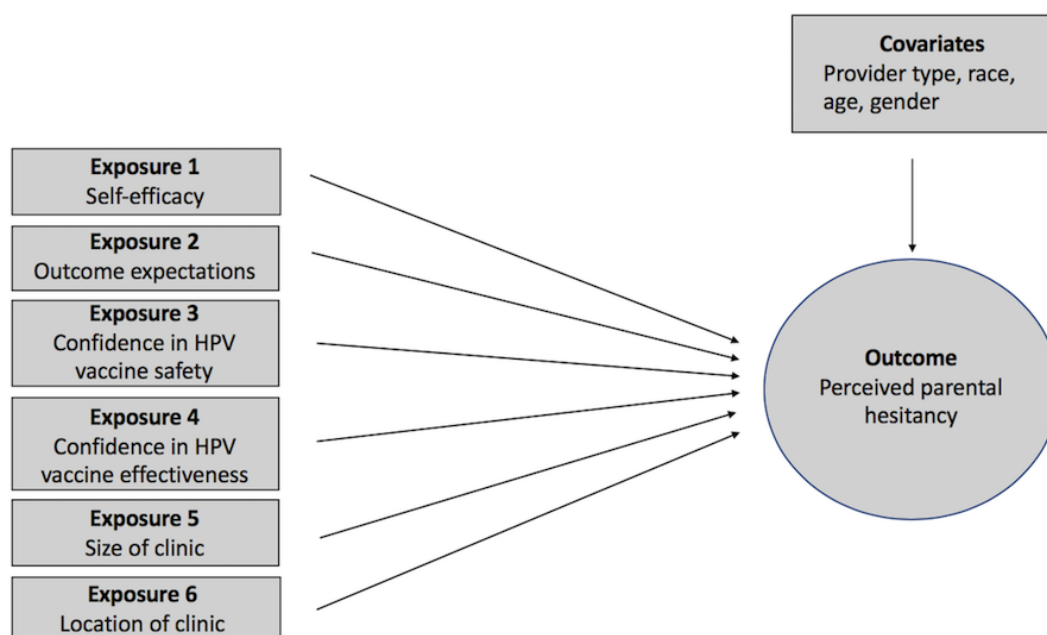
### ***Perceived Parental Hesitancy by Providers***

This is the primary outcome variable for this study. For this variable, we calculated a sum score from 7-items representing possible parental concerns, for which the providers rated how much they thought each one was a barrier to immunizing their patients against HPV (eg, parental concerns about HPV vaccine safety and parental mistrust of vaccines in general). The responses for each item were on a 4-point Likert scale ranging from not a barrier at all to a major barrier. Before the analysis, the scores of the individual items were recoded by using a 0 to 100 range with 0=not a barrier at all, 33=a minor barrier, 67=somewhat of a barrier, and 100=a major barrier, for consistency with the other scales that were measured using 4-point Likert scales. Higher scores represented greater levels of perceived parental hesitancy. This measure was adopted from Farias et al (2017) [19]. The authors did not report on the process used to develop the items or the psychometric properties of the scale. We selected this measure as we could not locate any other validated measures for perceived parental hesitancy for providers. In our sample, the provider-perceived parental hesitancy scale demonstrated good internal consistency with Cronbach alpha=.73.

### ***Covariates***

Provider age was a continuous variable measured in years. Providers self-identified their race/ethnicity as White, Black, Hispanic, Asian, or other. To create a dichotomous variable for race for this analysis, Black, Hispanic, Asian, and other were combined in the category *nonwhite*, because of low number of participants in these categories. Provider gender was represented with the categories of male and female. Provider type included physician, NP, or PA. For this study, NPs and PAs were combined into 1 category as nonphysician providers because only 3 PAs were in this dataset. Years of provider experience was not included as a covariate because it was highly correlated with age (Pearson's  $r=0.90$ ,  $P<.001$ ; results not shown). [Figure 1](#) depicts the relationship between all of the variables.

**Figure 1.** Depiction of variables. HPV: human papillomavirus.



## Statistical Analysis

### *Provider Characteristics by Provider Type*

First, for descriptive purposes, provider-level demographic characteristics (age, race, and gender) were summarized for the overall sample and compared by provider type (ie, physicians and NPs/PAs) using Wilcoxon rank-sum test for continuous variables and Fisher's exact test for categorical/binary variables. Continuous variables were summarized with median and quartiles, and categorical variables were summarized with frequencies and proportions.

### *Reasons for Perceived Parental Human Papillomavirus Vaccine Hesitancy by Provider Type*

Second, for descriptive purposes, each of the individual items representing provider-perceived barriers of parental HPV vaccine hesitancy was summarized using frequencies and proportions, and also compared by provider type using Wilcoxon rank-sum test.

### *Perceived Human Papillomavirus Vaccine Hesitancy Scale and Exposure Variables by Provider Type*

Next, the outcome variable (ie, perceived HPV vaccine hesitancy scale) and the exposure variables were summarized for the total sample with median and quartiles for continuous variables, and with frequencies and proportions for categorical variables. The outcome and exposures were compared by provider type, using Wilcoxon rank-sum test and Fisher's exact test.

### *Linear Regression Analysis for Perceived Parental Human Papillomavirus Vaccine Hesitancy by Provider-Level Factors and Clinic-Level Factors*

The objective of the primary analysis was to identify provider- and clinic-level factors associated with parental HPV vaccine hesitancy as perceived by providers. To estimate the associations between the outcome and the provider-level exposure variables

of interest (ie, self-efficacy, outcome expectation, confidence in HPV vaccine efficacy, and confidence in HPV vaccine safety), a multilevel linear regression model was fit, taking one exposure variable at a time. We used linear mixed-effects models to account for clustering at the clinic level (ie, correlations between observations from the same clinic) through a random effect. Due to small numbers of responses in some of the categories, confidence in efficacy and confidence-in-safety variables were dichotomized into *very high* and *other*. The model also included age, race, gender, and type (physician NP/PA) of the providers. To investigate the clinic-level characteristics and their association to the primary endpoint, a similar multilevel model was fit with additional clinic-level variables: size and location. Clinic size was represented by the total number of providers and location was categorized into urban/rural. The provider-level variables (ie, age, race, gender, and type) were also included in this model. A significance level of  $\alpha=.05$  was selected. R version 3.5 by the R Foundation was used for all statistical analyses [25].

## Results

### *Provider Characteristics by Provider Type*

The survey was sent to all 187 providers located within the 23 clinics. Of these, 137 completed the survey, and all were used in this analysis except for 1 participant that did not finish the survey and had incomplete data. Table 1 provides demographic characteristics of the population. The median age of the 98 physicians was 47.0 (Quartiles: 42.0-52.0) and 33.0 (Quartiles: 28.2-39.8) for the 38 NPs/PAs. Among physicians, the majority were white (85%) and female (61%). Among NPs and PAs, almost all were white (97%) and female (95%). Overall, there were significant differences by provider type for age ( $P<.001$ ) and gender ( $P<.001$ ; Table 1). As it relates to a clinic location, there were 18 clinics in urban areas and 5 clinics in rural areas. For clinic size, the overall median was 5 providers (Quartiles: 4.0-6.5; Results not shown).

**Table 1.** Provider characteristics at baseline by provider type.

Variable	All providers (N=136)	Physicians (n=98)	NPs <sup>a</sup> /PAs <sup>b</sup> (n=38)	P value
Age (LQ <sup>c</sup> -UQ <sup>d</sup> ), years	45.0 (35.0-51.0)	47.0 (42.0-52.0)	33.0 (28.2-39.8)	<.001
<b>Race, n (%)</b>				<b>.07</b>
White	119 (88)	83 (85)	36 (97)	— <sup>e</sup>
Nonwhite	16 (12)	15 (15)	1 (3)	—
<b>Gender, n (%)</b>				<b>&lt;.001</b>
Male	40 (29)	38 (39)	2 (5)	—
Female	96 (71)	60 (61)	36 (95)	—

<sup>a</sup>NPs: nurse practitioners.

<sup>b</sup>PAs: physician assistants.

<sup>c</sup>LQ: lower quartile.

<sup>d</sup>UQ: upper quartile.

<sup>e</sup>Not applicable.

### Reasons for Perceived Parental Human Papillomavirus Vaccine Hesitancy by Provider Type

The individual items representing reasons for parental HPV vaccine hesitancy as perceived by provider type are described in [Multimedia Appendix 1](#). Among all providers, the majority reported the following as perceived barriers (ie, combination of somewhat of a barrier and a major barrier categories): parental concerns of HPV vaccine safety (88%), parental belief in child is too young for HPV vaccine (78%), parental belief that child is not at risk of HPV infection through sexual contact (70%), and parental mistrust in vaccines in general (59%). Yet, the least commonly reported barriers (ie, combination of somewhat or major barrier categories) were parental concern of getting too many shots during a visit (ie, HPV, Tdap, and Meningococcal; 40%), parental concerns about HPV vaccine efficacy (30%), and parental concerns about out-of-pocket costs (13%). Similar results were found among physicians versus NPs/PAs, except for significant differences in perception toward being too young to get the vaccine (81% vs 73%;  $P=.04$ ) and parental concern

regarding their child getting too many shots during a visit (44% vs 9%;  $P=.003$ ), with physicians being more likely to perceive these as somewhat or a major barrier than NP/PA.

### Perceived Human Papillomavirus Vaccine Hesitancy and Exposure Variables by Provider Type

[Table 2](#) summarizes the outcome variable (perceived HPV vaccine hesitancy) and the exposure variables for total sample and by provider type. For perceived barriers to HPV vaccination (outcome variable), the median score for all providers was 52.0, with physicians having greater perceived barriers than NPs/PAs ( $P=.009$ ). The exposures did not differ by provider type. For all providers, the median score was 75.0 for *self-efficacy* and 62.0 for *outcome expectations*. Among physicians, the majority had high to very high confidence in the effectiveness of the HPV vaccine (95%) and safety of the HPV vaccine (97%). Similarly, NPs/PAs had high to very high confidence in the effectiveness of the HPV vaccine (92%) and safety of the HPV vaccine (89%).

**Table 2.** Outcome and exposure variables by pediatric provider type.

Variable	All providers (N=136)	Physicians (N=98)	NPs <sup>a</sup> /PAs <sup>b</sup> (N=38)	P value
Outcome: perceived parental hesitancy (LQ <sup>c</sup> -UQ <sup>d</sup> )	52.0 (43.0-62.0)	57.0 (43.0-67.0)	48.0 (38.0-57.0)	.009
<b>Exposures, (LQ-UQ)</b>				
Self-efficacy (Q)	75.0 (62.0-88.0)	75.0 (62.0-88.0)	71.0 (60.0-88.0)	.43
Outcome expectations (Q)	62.0 (50.0-69.0)	62.0 (50.0-69.0)	56.0 (50.0-69.0)	.89
<b>Confidence: HPV<sup>e</sup> vaccine effectiveness, n (%)</b>				
Very/somewhat low	1 (1)	0 (0)	1 (3)	— <sup>f</sup>
Neutral or not sure	7 (5)	5 (5)	2 (6)	—
High	41 (31)	30 (31)	11 (31)	—
Very high	85 (63)	63 (64)	22 (61)	—
<b>Confidence: HPV vaccine safety, n (%)</b>				
Very/somewhat low	1 (1)	0 (0)	1 (3)	—
Neutral or not sure	6 (5)	3 (3)	3 (8)	—
High	46 (35)	34 (35)	12 (33)	—
Very high	80 (60)	60 (62)	20 (56)	—

<sup>a</sup>NPs: nurse practitioners.<sup>b</sup>PAs: physician assistants.<sup>c</sup>LQ: lower quartile.<sup>d</sup>UQ: upper quartile.<sup>e</sup>HPV: human papillomavirus.<sup>f</sup>Not applicable.

### Linear Regression Analysis for Perceived Parental Human Papillomavirus Vaccine Hesitancy by Provider-Level Factors and Clinic-Level Factors

**Table 3** reports the associations between the provider's perceived parental HPV vaccine hesitancy score and provider's *self-efficacy*, *outcome expectations*, *confidence in vaccine effectiveness*, and *confidence in vaccine safety* based on the mixed-effects models, adjusting for age, race, gender, and provider type. A 10-point increase in *self-efficacy* was associated with a 2.9-point (95% CI 1.2-4.7) decrease in perceived parental HPV vaccine hesitancy when adjusting for covariates ( $P=.001$ ). Similarly, a 10-point increase in *outcome expectations* was associated with a 3.7-point (95% CI 1.8-5.8) decrease in perceived parental HPV vaccine hesitancy ( $P<.001$ ). For *confidence in HPV vaccine safety*, participants who had *very high* confidence on average scored 4.8 points lower on the perceived parental HPV vaccine hesitancy scale than the participants who had lower levels of confidence ( $P=.009$ ). No

significant association was found between perceived parental HPV vaccine hesitancy and *confidence in HPV vaccine effectiveness*. In all models, age, race, gender, and type of provider were not found to be significantly associated with the outcome, except the confidence-in-safety model, where female providers had a higher perceived parental HPV vaccine hesitancy by 6.9 points (95% CI 0.6-13.0;  $P=.03$ ; results not shown).

**Table 4** reports the associations of *clinic size* and *location* (town/rural vs city and non-MSA vs MSA) with perceived parental HPV vaccine hesitancy score. Including clinic-level variables in the model revealed no significant association between the clinic-level characteristics and perceived parental HPV vaccine hesitancy. Although adjusting for provider characteristics (age, gender, race, and type) and clustering by clinic, neither clinic size ( $P=.92$ ) nor town/rural ( $P=.87$ ) or non-MSA ( $P=.56$ ) was found to be significantly associated with the outcome.

**Table 3.** Association between perceived parental human papillomavirus vaccine hesitancy score and provider level exposures using mixed-effect model (the mixed-effects models included one study exposure at a time and adjusted for age, race, gender, and provider type).

Provider-level factors	Estimate	Standard error	t value	P value
Self-efficacy	-0.29	0.08	-3.43	.001
Outcome expectations	-0.37	0.09	-4.05	<.001
Confidence in vaccine effectiveness: very high versus other (ref)	-5.20	2.88	-1.80	.07
Confidence in vaccine safety: very high versus other (ref)	-4.8	2.77	-1.72	.009



**Table 4.** Association between perceived parental vaccine hesitancy score and clinic-level exposures (the model includes one study exposure and adjusts for age, race, gender, and type of the providers).

Clinic-level factors	Estimate	Standard error	<i>t</i> value	<i>P</i> value
Clinic size	0.11	1.12	0.10	.92
<b>Clinic location</b>				
Town/rural versus city (ref)	1.06	6.46	0.17	.87
Non-MSA <sup>a</sup> versus MSA (ref)	-4.53	7.68	-0.59	.56

<sup>a</sup>MSA: metropolitan statistical area.

## Discussion

### Principal Findings

We characterized perceived reasons for parental HPV vaccine hesitancy as perceived by pediatric providers. Not surprisingly, we found that the majority of providers perceived HPV vaccine safety, mistrust in vaccines, low perceived risk for HPV via sexual contact, and child's young age as major parental barriers to HPV vaccination. A handful of previous studies have sought to characterize perceived barriers to HPV vaccine hesitancy according to providers [19,20]. McRee et al (2014) found that child not being sexually active, perception of child not being susceptible to an HPV-related disease, discomfort with sex talks with their child, and concerns about vaccines in general as the most common perceived reasons of parental HPV vaccine hesitancy among providers in Minnesota in 2013 [20]. Although providers in our sample also reported some of these reasons for parental hesitancy, safety concern about the HPV vaccine was the top reason in our sample. This could represent a difference across states or a shift in hesitancy reasons over the 5 years since that survey was conducted. Provider concern about vaccine safety was associated with lower patient vaccination uptake according to Farias et al (2017) [19]. As provider-perceived barriers have been found to contribute to lower HPV vaccine uptake [19,21], further research is needed on a larger scale, statewide and nationally, to monitor perceived parental barriers according to providers and by type. This will continue to inform intervention targets and establish generalizability of our findings. In addition, future studies should identify if providers are overestimating and misinterpreting reasons for parental hesitancy compared with actual parent-reported sources of parental hesitancy to be used as intervention targets.

This study was the first to identify if perceived reasons for parental HPV vaccine hesitancy varied by the type of pediatric provider. We observed significant differences in perceived barriers (ie, concern of their child getting too many shots during a visit and being too young to get the vaccine) by provider type. These findings suggest parental perceived barriers can vary across providers, with physicians more likely to perceive these as a major barrier. A possible explanation for this variation could be if the type of educational training related to vaccine hesitancy differs between physicians and other providers. In addition, physicians may have experienced different interactions with parents compared with other providers, which may lead to differences in perceived parental barriers. Hence, tailored strategies or messages by provider type could be used in interventions to assist them in addressing HPV vaccine parents.

In this sample, the majority of the providers had high to very high levels of confidence in HPV vaccine safety and effectiveness, as well as high levels of outcome expectations and self-efficacy. The level of outcome expectations and self-efficacy was similar to another study [20], which shows that providers still have room to improve on these factors. A previous study found that providers with higher levels of self-efficacy and outcome expectations had more routine recommendations of the HPV vaccine and increased ability to address hesitant parents [20]. Due to the role these factors play in providers perceiving lower parental hesitancy, interventions aimed at training providers on how to address HPV vaccine hesitancy may benefit from targeting provider confidence in safety, self-efficacy, and outcome expectations.

To our knowledge, this is the first study to also identify provider and clinic-level factors associated with perceived parental barriers to HPV vaccine hesitancy according to providers. One explanation for the positive association between perceived parental barriers and self-efficacy, outcome expectations, and confidence in vaccine safety could be that providers who engage in unsuccessful encounters with HPV vaccine hesitant parents increase their perceived parental barriers to HPV vaccination while lowering their self-efficacy and outcome expectations. Furthermore, providers with low confidence in HPV vaccine safety may unintentionally transfer their own uncertainty to the parents of their patients and perceive that parents are more hesitant than they actually are [7].

Surprisingly, in viewing clinic-level factors associated with perceived provider barriers, clinic location was not found statistically significant. In 2017, rural areas had lower coverage rates for receipt of the first dose of the HPV vaccine compared with urban areas, with a difference of 11 percentage points [26]. This raises the question of whether HPV vaccination is lower in rural areas because parental hesitancy is more prevalent, or because providers are less likely to recommend the vaccine or recommend it effectively in rural areas due to perceived parental barriers to HPV vaccination. As physicians play a key role in parental acceptance, the lack of association here warrants more research to gain a better understanding of the factors influencing physician recommendations in rural areas.

### Limitations

This study was not without limitations. First, this was a cross-sectional study with a "snapshot" captured of factors influencing perceived parental HPV vaccine hesitancy according to pediatric providers. Therefore, we could only examine associations and not causality. Perceived provider hesitancy

could also influence the independent variables, and given the cross-sectional and correlational design, we could not test direction of causality. Nevertheless, this study contributes valuable information to the literature as the first to examine this question, and future research is needed to explore potential bidirectional relationships with the outcome variable using a longitudinal design or more complex relationships using a qualitative research. Second, we had a convenience sample of clinics and providers in Tennessee who participated in the larger study in 2018. Thus, the sample was limited to a subset of the pediatric provider population (ie, primarily white and female). The specific context of time and place could limit the generalizability of results to other regions of the country, given that Tennessee has relatively low levels of HPV vaccination; furthermore, perceived parental vaccine hesitancy could change over time as vaccination coverage increases. In addition, we were unable to test for differences in perceived barriers to HPV vaccination between NPs and PAs because of the small sample size. However, this was the first study to examine this question and will inform future studies in larger samples that can test this comparison. The measures (ie, self-efficacy, outcome expectations, and perceived parental hesitancy) adopted from previous studies were unvalidated at the time of study; however, we found them to have acceptable reliability. We included all of the demographic variables from the survey as covariates except for years of experience of the providers because of its strong correlation with age; we were unable to account for other potential unmeasured confounders. Given that the data were

self-reported, there was potential for social desirability and recall bias. Finally, because this study only surveyed providers and not parents, we could not assess how well the perceived reasons of the providers aligned with actual reasons for hesitancy of the parents. This study points to the need for future research to do so.

## Conclusions

Provider perceptions of parental barriers to HPV vaccine hesitancy are an important factor contributing to HPV vaccine uptake among parents [19,21]. Their perceptions of parent barriers may influence their likelihood to recommend the vaccine and how they communicate the recommendation [19], which is a major issue as their recommendation is the strongest predictor of HPV vaccine uptake [27,28] and parents prefer a strong provider recommendation [13,14]. Strategies are needed to effectively reduce provider-perceived barriers to parental HPV vaccine hesitancy and to assist providers in addressing these barriers in patient-provider communication. Our results suggest intervention targets to improve provider perceptions of parental barriers by addressing specific factors that may influence their perceptions. Particularly, intervention developers should consider addressing providers' self-efficacy, perceived outcome expectations, and confidence in HPV vaccine safety. Ultimately, addressing these provider-level factors may improve recommendation practices and communication strategies among providers for addressing hesitancy, to increase HPV vaccination rates among children of HPV vaccine hesitant parents.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Reasons for parental human papillomavirus vaccine (HPV) hesitancy as perceived by pediatric provider type.

[[PDF File \(Adobe PDF File\), 73KB - cancer\\_v5i2e13832\\_app1.pdf](#)]

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## Abbreviations

**CPF:** Cumberland Pediatric Foundation

**HPV:** human papillomavirus

**MSA:** metropolitan statistical area

**NP:** nurse practitioner

**PA:** physician assistant

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Original Paper

# Mediators of a Physical Activity Intervention on Cognition in Breast Cancer Survivors: Evidence From a Randomized Controlled Trial

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## Abstract

**Background:** Emerging research suggests that increasing physical activity can help improve cognition among breast cancer survivors. However, little is known about the mechanism through which physical activity impacts cancer survivors' cognition.

**Objective:** The objective of this secondary analysis examined physical and psychological function potentially linking physical activity with changes in cognition among breast cancer survivors in a randomized controlled trial where the exercise arm had greater improvements in cognition than the control arm.

**Methods:** A total of 87 sedentary breast cancer survivors were randomized to a 12-week physical activity intervention (n=43) or control condition (n=44). Objectively measured processing speed (National Institutes of Health Toolbox Oral Symbol Digit), self-reported cognition (patient-reported outcomes measurement information system [PROMIS] cognitive abilities), PROMIS measures of physical and psychological function (depression, anxiety, fatigue, and physical functioning), and plasma biomarkers (brain-derived neurotrophic factor, homeostatic model assessment 2 of insulin resistance, and C-reactive protein [CRP]) were collected at baseline and 12 weeks. Linear mixed-effects models tested intervention effects on changes in physical and psychological function variables and biomarkers. Bootstrapping was used to assess mediation. Exploratory analyses examined self-reported cognitive abilities and processing speed as mediators of the intervention effect on physical functioning.

**Results:** Participants in the exercise arm had significantly greater improvements in physical functioning (beta=1.23; 95% CI 2.42 to 0.03;  $P=.049$ ) and reductions in anxiety (beta=-1.50; 95% CI -0.07 to -2.94;  $P=.04$ ) than those in the control arm. Anxiety significantly mediated the intervention effect on cognitive abilities (bootstrap 95% CI -1.96 to -0.06), whereas physical functioning did not (bootstrap 95% CI -1.12 to 0.10). Neither anxiety (bootstrap 95% CI -1.18 to 0.74) nor physical functioning (bootstrap 95% CI -2.34 to 0.15) mediated the intervention effect on processing speed. Of the biomarkers, only CRP had greater changes in the exercise arm than the control arm (beta=.253; 95% CI -0.04 to 0.57;  $P=.09$ ), but CRP was not associated with cognition; therefore, none of the biomarker measures mediated the intervention effect on cognition. Neither cognitive abilities (bootstrap 95% CI -0.06 to 0.68) nor processing speed (bootstrap 95% CI -0.15 to 0.63) mediated the intervention effect on physical function.

**Conclusions:** Physical activity interventions may improve self-reported cognition by decreasing anxiety. If supported by larger studies, reducing anxiety may be an important target for improving self-reported cognition among cancer survivors.

**Trial Registration:** ClinicalTrials.gov NCT02332876; <https://clinicaltrials.gov/ct2/show/NCT02332876>

**KEYWORDS**

cognitive function; exercise; anxiety; neoplasms

## Introduction

### Background

The number of breast cancer survivors in the United States is expected to rise dramatically with its aging population and increased rates of breast cancer survival. Cognitive impairment is a disruptive and persistent condition that is common among breast cancer survivors [1]. Breast cancer survivors often show deficits on objective neurocognitive measures and self-reported measures of cognition, which assess different, yet important, aspects of cognition [2]. Cognitive difficulties can impact quality of life and ability to return to work [3]. Therefore, identifying effective interventions to improve cognition is a research priority in cancer survivorship [4].

A potential intervention is physical activity, recommended by the National Comprehensive Cancer Network for cancer-related cognitive dysfunction [4]. Breast cancer survivors often reduce physical activity after treatment and have low levels of physical activity [5]. The low activity levels in breast cancer survivors and the benefits of physical activity for cognition among noncancer populations [6] suggest that physical activity could be an important target for breast cancer survivors. Recent trials, including our 12-week intervention in 87 breast cancer survivors [7], have shown that increasing physical activity improves objective and self-reported cognition in cancer survivors [7-9]. As the intervention literature continues to grow, there is a need to understand the mechanisms driving the effects of physical activity on cognition [9].

A hypothesized mechanism linking physical activity with cognition is improvements in physical and psychological function. Problems with self-reported cognition have consistently been associated with poorer physical function, anxiety, depression, and fatigue, which are often elevated or impaired in cancer survivors [10-12]. Physical activity in cancer survivors can improve all these aspects of physical and psychological function [13-15]; therefore, physical and psychological function may mediate the relationship between physical activity and self-reported cognition. A longitudinal observational study in 1477 breast cancer survivors found that distress and fatigue were on the pathway between physical activity and self-reported cognition [16]. Physical and psychological function factors may also be associated with objective neurocognitive function. Prospective studies in healthy older adults have shown that poor physical function can predict future cognitive impairment [17-19]. A cross-sectional study in 299 breast cancer survivors found that physical activity was related to improved executive function and working memory and that the effect of physical activity on cognition was partially explained by physical activity's influence on fatigue [20]. To our knowledge, no randomized controlled trials have explored aspects of physical and psychological function as mediators of the effect of physical activity on cognition in cancer survivors. Given the high prevalence of impaired physical and

psychological function in breast cancer survivors and the strong connection between cognition and physical activity, improvements in physical and psychological function are plausible mechanisms through which physical activity may improve cognition [21].

Although cognitive and physical function have been shown to be related among cancer survivors [22,23], the direction of this relationship has not been studied. Evidence from cohort studies and randomized controlled trials in older adults suggests that cognitive impairments may precede physical decline [24,25]. Therefore, improvements in cognition may mediate the effects of physical activity on improved physical function.

Physical activity is thought to positively influence cognition via several biological mechanisms including increased brain-derived neurotrophic factor (BDNF), improved metabolic function, and reduced systemic inflammation. BDNF is a biomarker of brain health. BDNF levels are correlated with processing speed [26] and are significantly elevated after aerobic physical activity [27]. In noncancer populations, BDNF mediates the effects of physical activity on neurocognitive outcomes [28] and is positively related to objective [29] and self-reported [30] cognition in cancer patients. BDNF is regulated by energy balance, insulin, and inflammatory cytokines; thus, it is likely part of a central mechanism through which physical activity integrates with elements of metabolism to impact cognition. In fact, measures of metabolic dysfunction, for example, insulin resistance measured by the homeostatic model assessment of insulin resistance (HOMA-IR) or homeostatic model assessment 2 of insulin resistance (HOMA2-IR), calculated using fasting plasma insulin and glucose) [31,32], and systemic inflammation, for example, levels of C-reactive protein (CRP), are inversely associated with physical activity [33,34] and cognitive performance [33,35]. Insulin resistance/HOMA-IR is associated with cognitive decline in diabetic [36] and nondiabetic populations [37,38]. Routine physical activity is anti-inflammatory [10] and improves insulin sensitivity [39]. Physical activity interventions in cancer survivors result in beneficial effects on inflammation and insulin pathway biomarkers [39]. Interestingly, exercise frequency and an anti-inflammatory genotype *each* predicted better cognitive performance in a sample of breast cancer survivors [40]. Other accumulating evidence supports a direct link between inflammation and cognition in breast cancer survivors. In breast cancer patients studied before and up to 2 years post treatment, CRP levels were inversely correlated with cognition [41]. Breast cancer survivors have elevated systemic inflammation that is prevalent for decades post treatment and that is associated with cognitive decline [42,43]. In noncancer populations, CRP and insulin resistance have been associated with neurocognitive impairment [44]. Therefore, BDNF, systemic inflammation, and insulin resistance are potential putative mechanisms that

could causally link physical activity with cognition in cancer survivors.

## Objectives

The secondary analysis (this study) examined physical and psychological function and biological mechanisms potentially linking physical activity with changes in objective and self-reported cognition among breast cancer survivors enrolled in a 12-week randomized controlled trial. In the primary study of 87 breast cancer survivors, the exercise arm had greater improvements in objectively measured processing speed and self-reported cognitive abilities than the control arm [7]. The primary aim of this analysis was to explore whether proposed physical and psychological function measures (depression, anxiety, fatigue, and physical functioning) and mechanistic biomarkers (BDNF, HOMA2-IR, and CRP) mediated intervention effects on cognition. For the mediation analyses, the following steps were taken: (1) intervention effects on potential mediators (physical/psychological function/biomarkers) were examined, (2) associations between potential mediators (physical/psychological function/biomarkers) with objectively measured processing speed and self-reported cognitive abilities were examined, and (3) if changes in potential mediators (physical/psychological function/biomarkers) mediated the relationship between the intervention effect on objectively measured processing speed and self-reported cognitive abilities was tested. We a priori hypothesized that, compared with breast cancer survivors in the control arm, participants in the exercise arm would have improvements in physical and psychological function and biomarkers, and that these factors would mediate the relationship between physical activity and cognitive outcomes. To address uncertainties about the directionality of the relationship between physical function and cognition, we also conducted exploratory analyses assessing self-reported cognitive abilities and objectively measured processing speed as mediators of the relationship between physical activity and physical function.

## Methods

### Participants

A total of 87 breast cancer survivors were enrolled in a randomized controlled trial of a 12-week physical activity intervention [21]. Data were collected from February 2015 to July 2016. The study was approved by the University of California (UC) San Diego Institutional Review Board (protocol number 140694), and all participants provided written informed consent. The trial was registered on ClinicalTrials.gov (NCT02332876).

Eligible participants were female breast cancer survivors who were aged 21 to 85 years, who completed breast cancer surgery less than 5 years ago, and who completed chemotherapy or radiation treatment. Other inclusion criteria included the following: self-reporting less than 60 min of moderate-to-vigorous physical activity (MVPA) in 10-min bouts per week; self-reported foggy or worsening of memory, thinking, or concentration; and internet access. Exclusion criteria included the following: any medical condition that could preclude safe participation in an unsupervised physical activity

intervention and other primary or recurrent invasive cancer within the last 10 years.

## Procedures

Detailed information on study procedures and the intervention have been published [21]. Briefly, women were primarily recruited through cancer registries. Potential participants were phone-screened for eligibility and then scheduled for an in-person visit at UC San Diego Moores Cancer Center, during which participants completed questionnaires, a fasting blood draw, and neurocognitive tests. Height and weight were measured. Next, participants received an ActiGraph GT3X+ accelerometer (ActiGraph, LLC.) to wear for 7 days and return at the randomization visit. At the randomization visit, 87 breast cancer survivors were randomized in a 1:1 allocation ratio to receive either a 12-week physical activity intervention (exercise arm, n=43) or waitlist wellness contact control condition (control arm, n=44). All baseline measures were repeated at 12 weeks. A participant from each arm was lost to follow-up, resulting in 98% retention (exercise, 42/43 and control, 43/44) [7].

### Physical Activity Intervention (Exercise Arm)

Participants randomized to the exercise arm completed an in-person visit that lasted 30 min to 45 min. At this visit, participants were first taken on a 10-min walk to learn what moderate-intensity activity felt like. Then, using motivational interviewing techniques, the interventionist helped the participant set a personalized physical activity goal. Participants could set any starting goal they wanted and were encouraged to gradually increase aerobic exercise to meet the study goal of at least 150 min of MVPA per week [45]. To support self-monitoring and accountability, they received a Fitbit One and were informed that the interventionist could see the Fitbit data and would be checking on their activity weekly. Interventionists provided feedback on Fitbit data during 2 scheduled phone calls at the 2- and 6-week time points and as needed. Participants also received emails every 3 days throughout the intervention with theory-based content and reminders to wear and sync their Fitbit.

### Waitlist Wellness Contact Control Condition (Control Arm)

Participants randomized to the control arm received emails on the same schedule as the exercise arm. Emails focused on various women's health topics of interest to breast cancer survivors including general brain health, healthy eating, and reading nutrition labels. Content of the emails were specifically chosen to be topics of interest but were very brief and strictly informational to not encourage behavior change. After completing the 12-week measures, participants in the control arm received the physical activity intervention described above.

## Measures

### Physical and Psychological Function

Anxiety, depression, fatigue, and physical function were measured using patient-reported outcomes measurement information system (PROMIS) measures developed by the National Institutes of Health (NIH) for cancer survivors. Using a computer adaptive format, questions assessed symptoms over

the past 7 days. Higher scores on the physical functioning measure indicate better functioning. Higher scores on all other measures indicate worse functioning. Raw scores for each PROMIS measure are reported on a standardized T-score metric (mean 50, SD 10), separately for each measure [46]. PROMIS measures have undergone rigorous evaluation and validation in cancer survivors and have shown responsiveness to both improvements and declines in symptoms and function over time, as well as sensitivity to detect differences between groups for which a change is expected versus comparison groups for which no change is expected [47]. In line with previous studies in cancer survivors, a clinically meaningful difference was defined as a 3-point difference in scores [46,48].

### **Biomarkers**

Biomarkers of interest were BDNF, CRP, and HOMA2-IR. In total, 12 mL of fasting blood was collected in EDTA tubes; plasma was immediately isolated by centrifugation at 4°C, then aliquoted and stored at -80°C. Biomarkers were assayed after all data collection was completed to minimize batch-to-batch variation. Paired samples were run side by side, and quality control and normalization control samples were included in all assay runs. Glucose concentrations were measured using a standard glucose oxidase method (YSI 2900 Biochemistry Analyzer). Plasma BDNF, CRP, and insulin concentrations were determined using high-sensitivity immunoassays (Meso Scale Discovery: custom kit [BDNF], catalog number K15198D [CRP], and catalog number K15164C, [insulin]) run at the NIH-funded UC San Diego Clinical and Translational Research Institute Biomarker Laboratory. BDNF concentrations for individual samples were normalized to the normalization control sample set run in quadruplicate on each of the 3 assay plates. Coefficients of variance were 6.1% (BDNF), 2.9% (CRP), 7.1% (glucose), and 4.6% (insulin). HOMA2-IR was calculated using fasting glucose and insulin concentrations [49] using the publicly downloadable HOMA2 calculator [50]. HOMA2-IR is a model-derived estimate of insulin resistance that uses a more sophisticated calculation than the linear equation for HOMA-IR.

### **Cognitive Functioning**

Processing speed was measured with the Oral Symbol Digit test from the NIH Toolbox Cognition Domain [51]. This computer-based version of the Wechsler Adult Intelligence Scale Digit-Symbol-Coding test has been validated and normed in individuals aged 3 to 85 years. The test provides a raw score (possible range: 0-144), with higher scores indicating better processing speed [51].

Self-reported cognition was measured with the PROMIS cognitive abilities questionnaire that assesses patient-perceived functional abilities in the past 7 days. Higher scores on the cognitive abilities measure indicate more positive perceptions of cognition. This measure provides standardized T-scores that have demonstrated good reliability and validity with previous measures including the functional assessment of cancer therapy-cognitive function measure [52].

### **Physical Activity**

Change in MVPA was measured with the ActiGraph GT3X+. Wear time was screened for in Actilife software (ActiGraph)

using the guidelines by Choi et al [53]. Sufficient wear time was defined as 5 days with more than or equal to 600 min or 3000 min across 4 days. Time spent in minutes of MVPA was derived using the 1952 cut point [54]. The ActiGraph has been validated against heart rate telemetry and total energy expenditure [55].

### **Demographic and Clinical Variables**

Self-reported demographics, including age, education, income, race/ethnicity, and marital status, were collected at baseline. Body mass index (BMI) was calculated from height and weight measurements collected at baseline. Breast cancer information and treatment details were obtained from medical charts.

### **Statistical Analysis**

Unless otherwise specified, all analyses were conducted using SAS version 9.4 (SAS Institute, Inc). All analyses were performed using an intent-to-treat principle. Longitudinal random-effects models were developed. This method uses all available data, does not omit subjects with missing data, and provides unbiased results provided the data conform to a *missing at random* missing data mechanism. Group differences in baseline characteristics were assessed using *t* tests and chi-square tests. Mixed-effects regression models with a subject-level random intercept and an unstructured covariance structure, as determined by model Akaike Information Criterion comparisons in the main effects models, were used for all other models. Models assessing intervention effects on repeated measures (at baseline and 12 weeks) of anxiety, depression, fatigue, physical function, and biomarkers (BDNF, HOMA2-IR, and CRP) included fixed effect terms for group, time point (baseline or 12 weeks), and time-by-group interaction. Contrasts were used to calculate the difference of change based on the regression model when examining group differences. Each outcome was assessed in a separate model. All biomarkers were log transformed before analyses to correct for right-skewed residuals.

Assuming a 2-sided test with an alpha of .05 and a sample size of 80 with 1:1 randomization to treatment or control, there was 80% power to detect a main effect of 0.32.

### **Mediation Analysis**

Owing to the small sample size, we chose an a priori significance level of  $P < .10$  to assess mediation. Mediation analyses were based on the approach of Baron and Kenny [56]. This approach states that the following conditions must be met for a test of potential mediation: (1) the independent variable (group) has a significant effect on the mediator (physical/psychological function/biomarker)—path *a*, (2) the mediator (physical/psychological function/biomarker) is associated with the outcome variable (cognition)—path *b*, and (3) the independent variable (group) has a significant effect on the outcome variable (cognition)—path *c*. If these conditions are met, a final analysis involves a multivariable model of the independent variable (group) predicting change in the outcome variable (cognition), controlling for the mediator (physical/psychological function/biomarker)—path *c'*. Path *c* (intervention effect on cognition) was previously published [7], and only 2 of the cognition measures, processing speed and



self-reported cognitive abilities, met our a priori significance level to be included in this mediation analyses.

In the mediation analysis, a drop in predictive power from path  $c$  to path  $c'$  (the indirect effect) suggests the existence of a mediation effect. The significance of this drop in predictive power was conducted using bootstrapping, whereby the indirect effect ( $c-c'$ ) was generated 200 times, and this sampling distribution was used to determine bounds for the 95% CI of the indirect effect. Bootstrapping was performed in R [57,58]. As we had a repeated measured design, we used the lme4 package [59] to apply the repeated measures mixed-effects model to all steps in the mediation analysis. Mediation analysis was conducted for all physical or psychological function or biomarker variables found to have a significant path  $a$ ,  $b$ , and  $c$  at the  $P < .10$  level. Intervention effects on cognition were reported in the main outcomes analysis for the study [7]. The main effects of group on cognition were determined similar to our main effects model described above. A mixed-effects regression model of each cognition variable of interest included fixed effect terms for group, time point (baseline or 12 weeks), and time-by-group interaction [7].

Exploratory analyses testing self-reported cognitive abilities and objectively measured processing speed as mediators of the intervention effect on physical function used the same mediation models and bootstrapping procedure described above.

## Results

### User Statistics

Participants ( $n=87$ ) were, on average, aged 57 (SD 10.4) years and 30 (SD 16.7) months post breast cancer surgery. Majority of the participants were diagnosed with stage 1 disease (61%, 53/87), received chemotherapy (53%, 46/87), and were taking an aromatase inhibitor or tamoxifen (70%, 61/87) at the time of study enrollment. Mean T-scores on the physical and psychological function measures ranged from a mean of 50.4 (SD 7.98) for depression to a mean of 55.2 (SD 7.72) for anxiety across the study arms. See Table 1 for baseline characteristics stratified by study arm; there were no significant differences between the exercise and control arms in baseline characteristics ( $P > .05$ ).

**Table 1.** Baseline characteristics by study arm among breast cancer survivors enrolled in a randomized trial of physical activity (N=87).

Baseline characteristics	Exercise intervention (n=43)	Wellness control (n=44)	P value
<b>Demographics<sup>a</sup></b>			
Age (years), mean (SD)	58.2 (11.37)	56.2 (9.30)	.35
<b>Education, n (%)</b>			
Some college or less	14 (33)	11 (25)	__ <sup>b</sup>
College graduate	18 (42)	22 (50)	—
Master's degree or higher	11 (26)	11 (25)	—
Married or living with partner, n (%)	32 (76)	31 (71)	.68
<b>Ethnicity, n (%)</b>			
Not Hispanic or Latino	35 (81)	37 (84)	—
Hispanic or Latino	8 (19)	7 (16)	—
<b>Race, n (%)</b>			
White	36 (84)	35 (80)	—
Nonwhite	7 (16)	10 (23)	—
Body mass index (kg/m <sup>2</sup> ), mean (SD)	26.7 (6.20)	27.3 (6.40)	.63
Time since breast cancer surgery (months), mean (SD)	30.3 (17.41)	30.0 (16.08)	.99
<b>Cancer stage, n (%)</b>			
Stage 1	27 (63)	26 (59)	—
Stage 2	12 (28)	15 (34)	—
Stage 3	4 (9)	3 (7)	—
Received chemotherapy, n (%)	23 (54)	23 (52)	.91
Current aromatase inhibitor or tamoxifen, n (%)	31 (72)	30 (68)	.69
<b>Physical and psychological functioning, mean (SD)</b>			
Physical functioning	50.2 (7.49)	51.8 (6.84)	.32
Anxiety	54.8 (8.51)	55.6 (6.95)	.65
Depression	50.0 (8.16)	50.7 (7.88)	.68
Fatigue	52.5 (7.64)	54.4 (9.17)	.29
<b>Biomarkers<sup>c</sup>, mean (SD)</b>			
Brain-derived neurotropic factor, normalized values	0.3 (0.19)	0.3 (0.29)	.32
Homeostatic model assessment 2 of insulin resistance	1.2 (0.98)	1.4 (1.12)	.58
Log C-reactive protein (pg/mL)	14.3 (1.29)	14.6 (1.32)	.31
<b>Cognition<sup>a</sup>, mean (SD)</b>			
Neurocognitive testing: processing speed (raw score)	73.7 (14.55)	77.7 (13.23)	.19
Self-reported cognitive abilities (T-score)	46.6 (5.96)	44.3 (5.27)	.06

<sup>a</sup>A secondary analysis of the mechanisms underlying the effect of an intervention on cognition is displayed here. The main effects of the intervention on cognition were previously published in a study by Hartman et al [7]

<sup>b</sup>Not applicable.

<sup>c</sup>Biomarker values were log transformed before analysis to correct for right-skewed residuals.

## Main Effects

The overall effects of the intervention on physical activity and cognitive outcomes have been published [7]. Briefly, the exercise arm had significantly greater increases in accelerometer-measured MVPA (mean min/day increase: 14.2

vs -0.7; beta=7.24;  $P<.001$ ) than the control arm from baseline to 12 weeks. Participants in the exercise arm showed significantly greater improvements in objectively measured processing speed than those in the control arm (mean increase score 7.0, SD 10.2 vs 3.0, SD 8.2; beta=2.01;  $P<.05$ ). The between-group difference in self-reported cognitive abilities

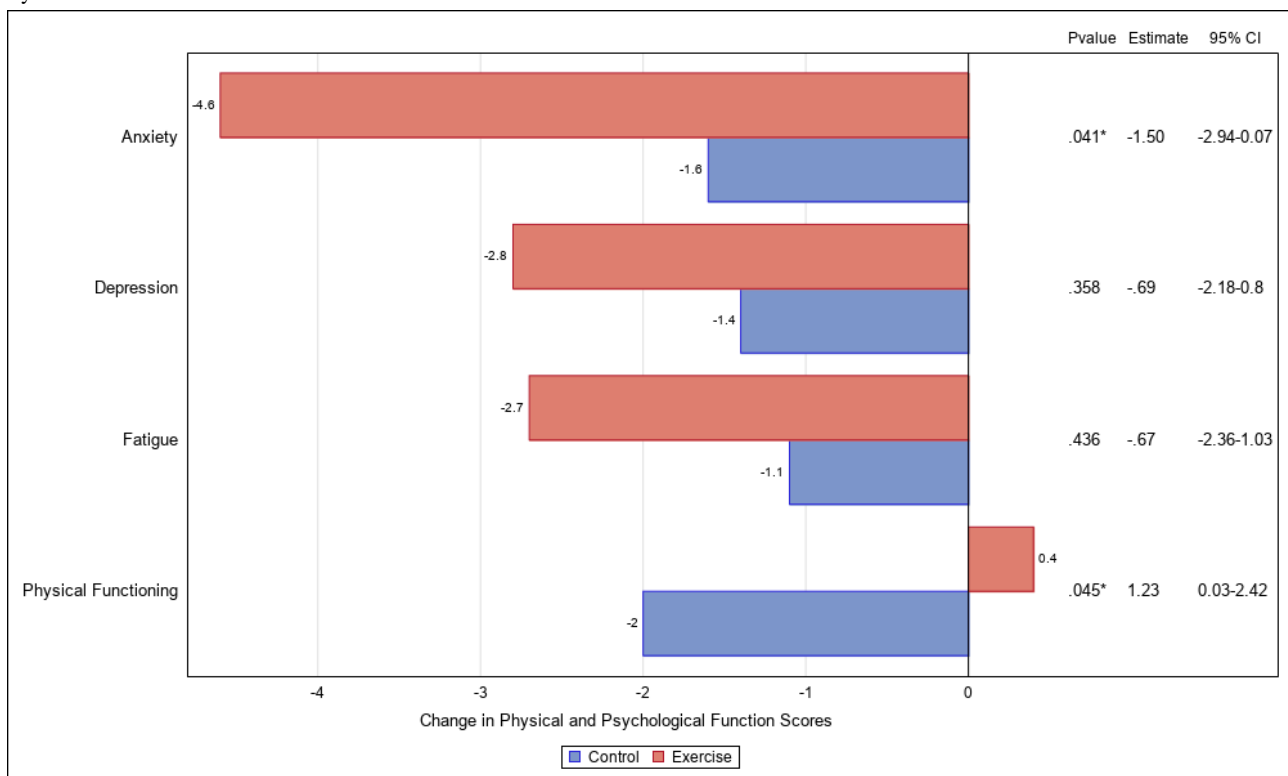
( $\beta=0.92$ ;  $P=0.09$ ) was not statistically significant, but the magnitude of the change within the exercise arm was suggestive of clinically meaningful improvement (average 2.7-point improvement from baseline to 12 weeks) [46].

### Physical and Psychological Function Mediation

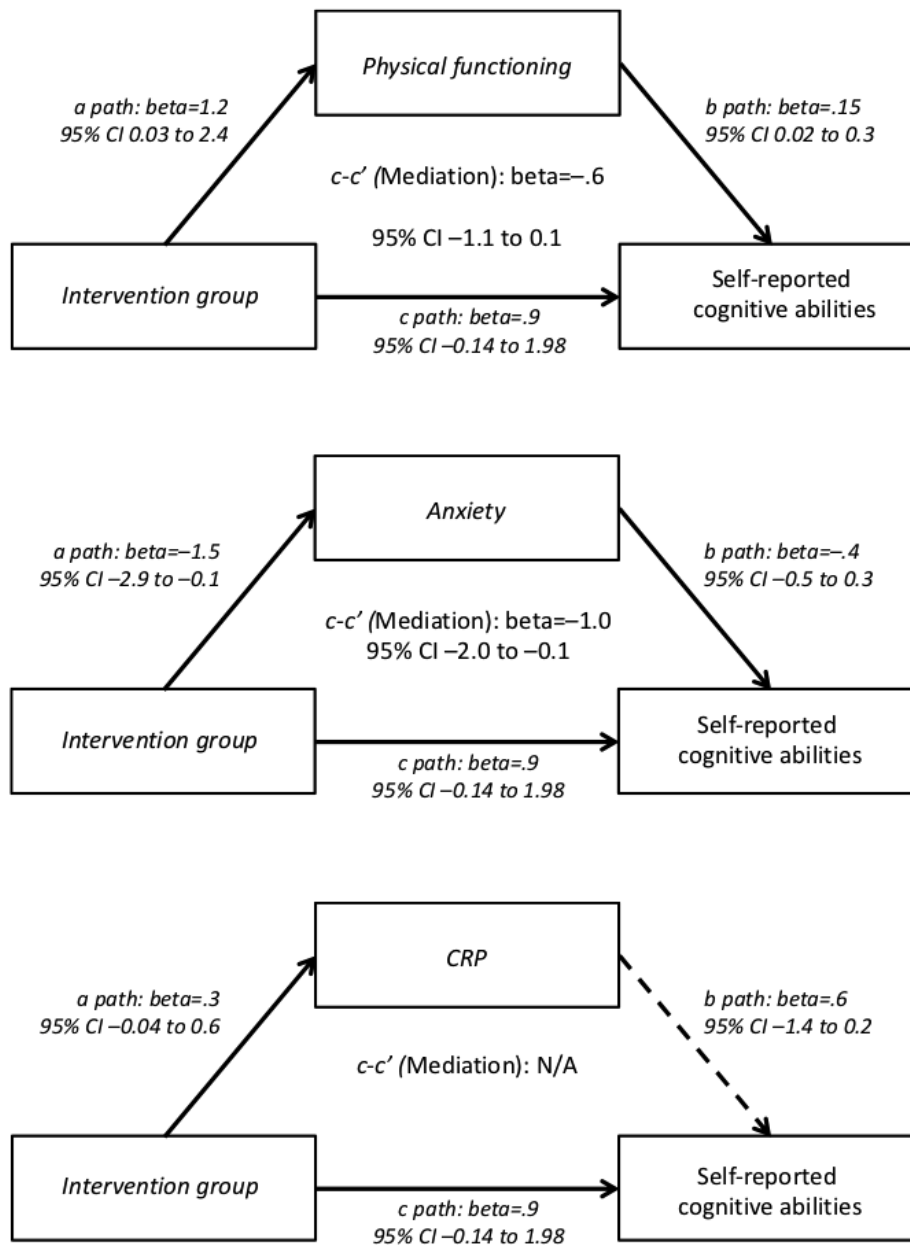
Changes in physical and psychological function measures from baseline to 12 weeks in the exercise versus control arms are presented in Figure 1. The exercise arm had significantly greater improvements in physical functioning than the control arm ( $\beta=1.23$ ; 95% CI  $-0.42$  to  $0.03$ ;  $P=0.049$ ). The exercise arm also showed significantly greater reductions in anxiety than the control arm ( $\beta=-1.50$ ; 95% CI  $-0.07$  to  $-2.94$ ;  $P=0.04$ ). Furthermore, changes in each of physical functioning and anxiety were significantly associated with the change in cognition (Figures 2 and 3 and Multimedia Appendix 1).

Therefore, conditions were met to test for the potential mediation effects of anxiety and physical functioning. Results indicate that anxiety significantly mediated the intervention effect on cognitive abilities (see Figure 2). Differences between the exercise and control arms in changes in cognitive abilities were, in part, because of greater decreases in anxiety among intervention participants compared with those in the control group (bootstrap 95% CI  $-1.96$  to  $-0.06$ ). Physical functioning did not mediate the intervention effect on cognitive abilities (bootstrap 95% CI  $-1.12$  to  $0.10$ ). Neither anxiety (bootstrap 95% CI  $-1.18$  to  $0.74$ ) nor physical functioning (bootstrap 95% CI  $-2.34$  to  $0.15$ ) mediated the effect of the intervention on processing speed (see Figure 3). Exploratory analyses found that neither cognitive abilities (bootstrap 95% CI  $-0.06$  to  $0.68$ ) nor processing speed (bootstrap 95% CI  $-0.15$  to  $0.63$ ) mediated the intervention effect on physical function.

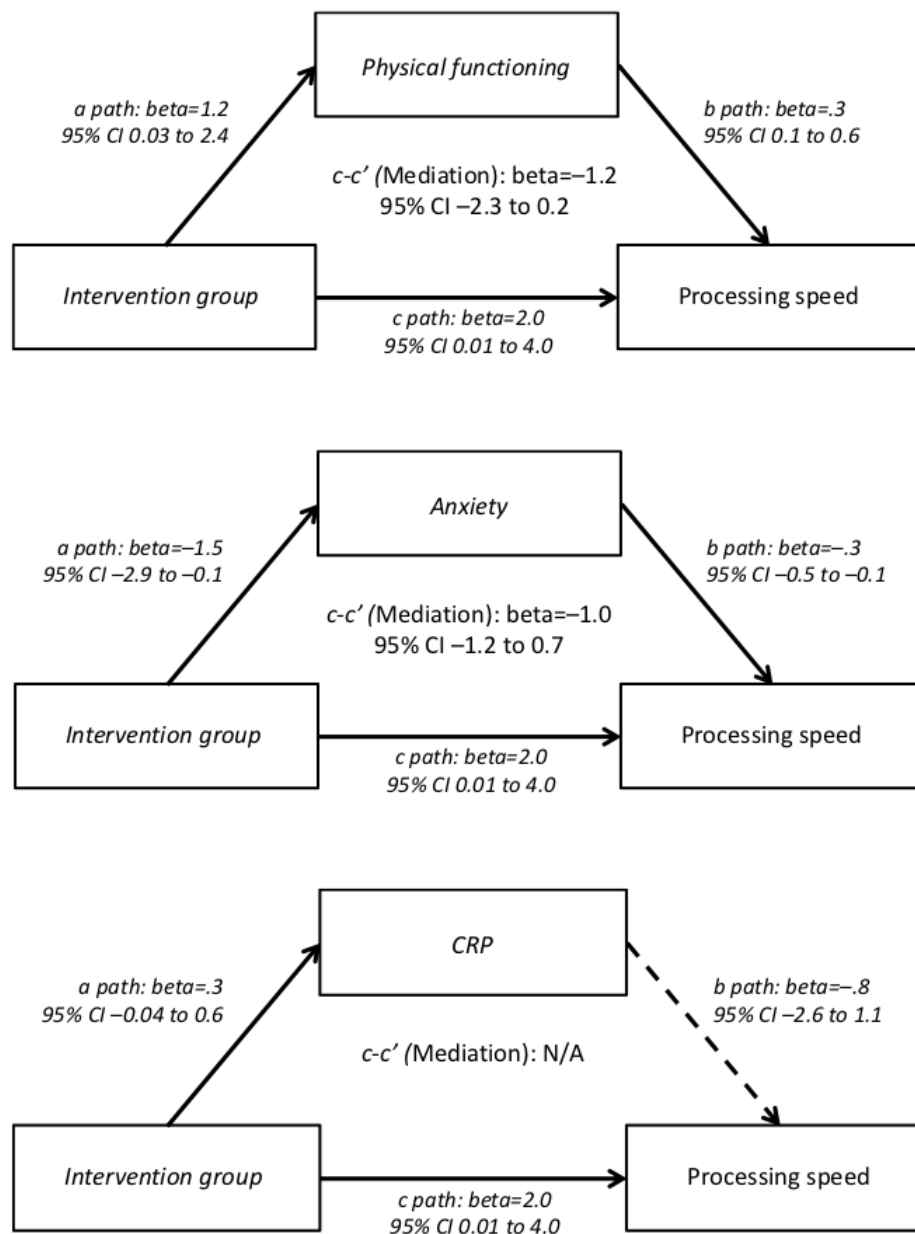
**Figure 1.** Differences in change from baseline to 12 weeks on measures of physical and psychological function by randomization group among breast cancer survivors enrolled in a randomized controlled trial of physical activity (N=87). Estimate: estimate of difference between groups for change in quality of life scores.



**Figure 2.** Bootstrap mediation analysis of anxiety, physical functioning, and C-reactive protein self-reported cognitive abilities among breast cancer survivors enrolled in a randomized trial of physical activity (N=87). Solid arrow lines indicate a *P* value less than .10. Dashed arrow lines indicate a *P* value greater than or equal to .10.



**Figure 3.** Bootstrap mediation analysis of anxiety, physical functioning, and C-reactive protein on processing speed among breast cancer survivors enrolled in a randomized trial of physical activity (N=87). Solid arrow lines indicate a *P* value less than .10. Dashed arrow lines indicate a *P* value greater than or equal to .10.



### Biomarker Mediation

The exercise arm had greater reductions in CRP than the control arm (beta=.253; 95% CI -0.04 to 0.57; *P*=.09; see path *a* in Figures 2 and 3 and Multimedia Appendix 1). Change in CRP was not associated with either measure of cognition (see path *b* in Figures 2 and 3 and Multimedia Appendix 1); therefore, mediation could not be tested. There were no between-group differences in changes in BDNF (beta=.092; 95% CI -0.25 to 0.43; *P*=.59) or HOMA2-IR (beta=.05; 95% CI -0.12 to 0.22; *P*=.55); therefore, conditions were not met to test for mediation, and no further analyses were conducted.

### Discussion

#### Principal Findings

This is the first known published randomized trial with breast cancer survivors to explore potential physical and psychological function and biological mechanisms underlying the effect of a physical activity intervention on objective and self-reported cognition. Results indicated that reductions in anxiety may have contributed to improvements in self-reported cognitive abilities, but there was no evidence of mediation for objectively measured processing speed or other measures of physical or psychological function. In addition, there was no evidence that the proposed biological mechanisms mediated the intervention effect on objective or self-reported cognition.

## Comparison With Previous Studies

Findings from this pilot study support the importance of anxiety for self-reported cognition and the potential for physical activity interventions to reduce anxiety in breast cancer survivors. Although previous physical activity intervention trials with cancer survivors that have examined physical or psychological function factors as possible mechanisms by which physical activity impacts cognition could not be identified, this finding is consistent with the published literature suggesting that self-reported cognition is likely a psychosocial aspect of cancer and indicator of psychological distress [60,61]. Self-reported cognition is consistently associated with other dimensions of psychological functioning such as depression and anxiety [2,61,62] that are elevated in breast cancer survivors and have been shown to improve with physical activity [14,63]. These results are also consistent with the notion that self-reported cognition is a distinct construct from objective neurocognitive function [2,64] and that there may be different mechanisms of the effects of physical activity on self-reported and objectively measured cognition.

Contrary to expectations, anxiety was the only physical or psychological function factor that was a significant mediator of the intervention effects on cognition. This finding may be because of the general lack of problems with physical and psychological function in our sample at baseline. It must be noted that, among all physical and psychological function factors examined, anxiety had the highest average scores at baseline (indicating higher levels of anxiety) and was the only variable to achieve a clinically meaningful change, which has been defined as a 3-point difference in scores for these measures [46]. Exploratory analyses to better understand the direction of the relationship between physical function and cognition were also nonsignificant. Research from the literature on aging suggests that both cognitive impairments precede physical declines [24,25], and physical declines precede cognitive declines [17,19]. However, this sample did not report impaired physical function at baseline, which might have limited the potential for physical functioning to mediate the relationship between physical activity and cognition or for cognition to mediate improvements in physical function. Fully powered trials, and trials targeting women with lower physical functioning, should be conducted to determine whether physical activity-associated improvements in day-to-day physical functioning are part of the causal pathway through which exercise improves cognition. Overall, this study provides preliminary evidence that in breast cancer survivors, physical activity interventions may improve self-reported cognition by reducing anxiety. Future studies with longer time frames and more distressed participants may be able to elicit clinically meaningful benefits to other aspects of physical and psychological functioning. Future research should also explore other aspects of physical and psychological function as potential mechanisms underlying the impact of physical activity interventions on cognition.

Although the intervention showed some reduction in systemic inflammation, as measured by CRP, this was not associated with cognition. Contrary to expectations, the intervention did not improve BDNF or HOMA2-IR. These findings may be because of having a sample with a normal to overweight BMI

and, on average, low HOMA2-IR, small sample size, and the short intervention duration. Previous larger physical activity randomized controlled trials with breast cancer survivors have found that the effects of physical activity on the insulin pathway are stronger among obese survivors [39]. BDNF has been understudied in breast cancer survivors; however, a review of randomized controlled trials of physical activity interventions in noncancer populations found improvements in BDNF in 3 out of 5 trials, with 2 of the trials being longer than 6 months [27]. Findings from this study suggest that among breast cancer survivors with a generally healthy BMI, neurotrophic factors, inflammation, or insulin pathways may not be the mechanisms for changes in cognition in a physical activity intervention. However, fully powered trials are needed to confirm these results.

As the research testing the impact of physical activity on cancer-related cognitive impairments grows, it is important to continue exploring the mechanisms that causally link physical activity and cognition. Future studies should consider factors related to biological and cellular aging. It has been hypothesized that MVPA can slow, or even reverse, cellular aging and thereby improve cognitive performance at the cellular level. This association is particularly relevant for cancer survivors who may experience accelerated aging caused by chemotherapy and psychological stress [1,65]. Other potential mechanisms may be related to the impact of physical activity on brain structure and function. Neuroimaging studies in breast cancer survivors have found structural changes including reduction in gray matter volume following chemotherapy, which has been associated with impairments in processing speed [66,67]. Although the direct impact of increasing physical activity on brain volume has not been tested, there is some evidence that hippocampal volumes are larger in breast cancer survivors with high cardiovascular fitness levels [68]. Physical activity also has the potential to increase cerebral blood flow, which may slow neurodegeneration [69]. Exploring whether the rate of cellular aging can be slowed by physical activity and whether physical activity can improve brain structure and function are important directions for future research with cancer survivors.

## Limitations and Strengths

The small sample size may not have provided sufficient power to detect significant mediation, and only bivariate mediation possibilities were considered. Subsequent studies with larger samples should consider multiple mediating mechanisms. Nonetheless, information gathered from these analyses can help generate new hypotheses about mechanisms and guide future studies to improve cognitive function in breast cancer survivors. The short duration and relative physical and mental health of the study population may also have limited our ability to detect mediation in the chosen mechanisms. Future studies with longer durations and more diverse populations that incorporate novel measures of cellular aging and neuroimaging are needed to continue advancing the field. Owing to the pilot nature of this study with limited power, we also did not adjust for multiple comparisons. In addition, these results are limited to a single measure of processing speed, and the findings cannot be generalized to other processing speed measures or aspects of cognition, such as memory, attention, and executive function,

which are often impacted by cancer and its treatments [70]. Another limitation is that the PROMIS measures may not have been sufficiently sensitive to the magnitude of change achieved in this study. A longitudinal study of almost 3000 cancer survivors demonstrated that effect sizes of 0.24 to 0.71 were needed to detect declines and improvements across different PROMIS measures [47].

Despite these limitations, the study had many strengths including the randomized design and objective measurement of physical activity. In addition, this study uniquely focused on physical and psychological function and biological mechanisms of action across both objective and self-report measures of cognition. Furthermore, bootstrap methods to assess mediation were used, which is recommended in small to moderate samples [71]. This

research extends what is known about the impact of physical activity on cognitive function to examine mechanisms of change. Identifying underlying mechanisms is critical for determining modifiable intervention targets and enhancing intervention efficacy.

### Conclusions

Results of this novel study provide preliminary evidence that an intervention that increases physical activity may improve self-reported cognition by decreasing anxiety. If supported by larger studies, recommending increasing physical activity may be an effective strategy for reducing anxiety and improving self-reported cognition among cancer survivors. Continued research in this area is needed to determine mechanisms of change for objectively measured cognition.

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### Conflicts of Interest

None declared.

### Multimedia Appendix 1

Bootstrap mediation analysis of anxiety, physical functioning, and C-reactive protein on processing speed and self-reported cognitive abilities among breast cancer survivors enrolled in a randomized trial of physical activity. (N=87).

[PDF File (Adobe PDF File), 299 KB - [cancer\\_v5i2e13150\\_app1.pdf](#) ]

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## Abbreviations

- BDNF:** brain-derived neurotrophic factor
- BMI:** body mass index
- CRP:** C-reactive protein
- HOMA2-IR:** homeostatic model assessment 2 of insulin resistance
- HOMA-IR:** homeostatic model assessment of insulin resistance

**MVPA:** moderate-to-vigorous physical activity

**NCI:** National Cancer Institute

**NIH:** National Institutes of Health

**PROMIS:** patient-reported outcomes measurement information system

**UC:** University of California

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Original Paper

# Feasibility of an Interactive Patient Portal for Monitoring Physical Activity, Remote Symptom Reporting, and Patient Education in Oncology: Qualitative Study

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## Abstract

**Background:** Digital health interventions, such as the use of patient portals, have been shown to offer benefits to a range of patients including those with a diagnosis of cancer.

**Objective:** This study aimed to explore the participant experience and perception of using an interactive Web-based portal for monitoring physical activity, remote symptom reporting, and delivering educational components.

**Methods:** Participants who were currently under treatment or had recently completed intensive treatment for cancer were recruited to three cohorts and invited to join a Web-based portal to enhance their physical activity. Cohort 1 received Web portal access and an activity monitor; cohort 2 had additional summative messaging; and cohort 3 had additional personalized health coaching messaging. Following the 10-week intervention, participants were invited to participate in a semistructured interview. Interview recordings were transcribed and evaluated using qualitative thematic analysis.

**Results:** A total of 17 semistructured interviews were carried out. Participants indicated that using the Web portal was feasible. Personalized messaging improved participant perceptions of the value of the intervention. There was a contrast between cohorts and levels of engagement with increasing health professional contact leading to an increase in engagement. Educational material needs to be tailored to the participants' cancer treatment status, health literacy, and background.

**Conclusions:** Participants reported an overall positive experience using the Web portal and that personalized messaging positively impacted on their health behaviors. Future studies should focus more on design of interventions, ensuring appropriate tailoring of information and personalization of behavioral support messaging.

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**KEYWORDS**

physical activity; patient Web portals; neoplasms

## Introduction

### Background

Digital health interventions may more effectively engage cancer patients to self-manage health-related concerns and behavior change [1]. The feasibility and effectiveness of Web portals have been tested in a variety of cohorts with chronic disease and may provide an opportunity to improve the delivery of cancer care [2]. Web portals have been demonstrated to offer a range of benefits to patients. It has been shown that patients with chronic diseases with access to Web portals have greater engagement in their treatment, lower levels of treatment-related distress, increased treatment satisfaction, and improved communication with health professionals [2-6]. However, the use of Web portals to support a multicomponent program of physical activity behavior change, remote symptom monitoring, and delivery of supportive care education for people with cancer has not been evaluated.

Physical activity levels vary throughout treatment and beyond in people diagnosed with cancer. Typically, physical activity decreases throughout and following intensive treatment such as chemotherapy, and commonly fails to reach prediagnosis levels [7,8]. This reduction in physical activity levels negatively impacts upon health status, including numerous treatment-related side effects and potentially mortality [9-11].

To support patients in an Australian comprehensive cancer center, we developed and piloted an interactive Web portal to support physical activity behavior change and symptom monitoring [12]. A range of features was available through the Web portal dependent on the cohort to which the patient was allocated. We have previously reported that feasibility and acceptability criteria were met, with engagement increasing with more feedback and health professional contact and was highest in those participants who received individual personalized messaging [12]. To provide greater depth of understanding of the patients' experiences and perceptions of the Web portal, semistructured interviews were needed.

### Objectives

In this analysis, we aimed to explore participants' experiences with the Web portal and their perceptions of its impact on their physical activity behavior. It was achieved through the use of semistructured interviews with participants following the 10-week intervention.

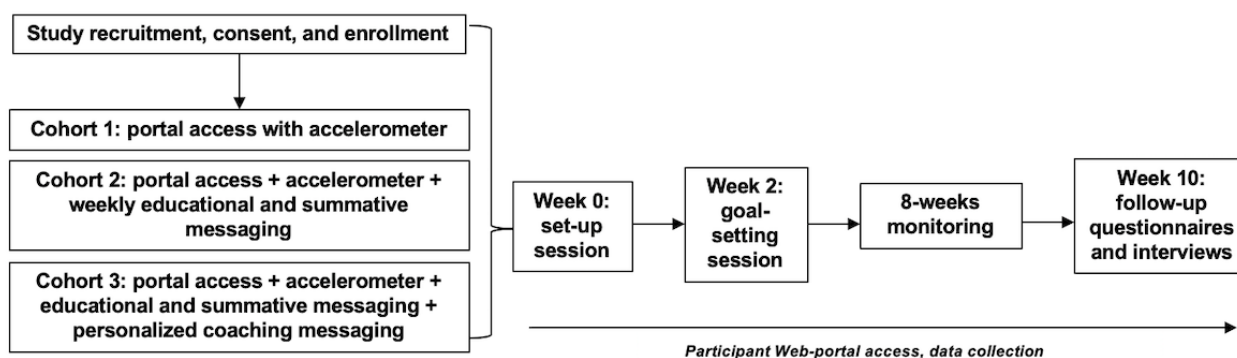
## Methods

### Study Design

This nested qualitative substudy was part of a larger feasibility study of a digital health care intervention for people with a history of cancer [12]. The intervention was developed utilizing evidence-based components of education, goal setting, monitoring, feedback, and motivation underpinned by the theoretical framework from Michie et al [13] and the transtheoretical model of behavior change [14]. Personalized health coaching elements were designed to deliver a motivational interviewing style intervention through a remote delivery platform [15]. Participants who had recently completed intensive anticancer therapy, and who were over 18 years of age and English speaking were recruited to 1 of 3 cohorts. Cohort 1 was provided access to the Web portal and given a commercially available wearable physical activity and sleep tracker (Misfit Shine) for the intervention period, along with emailed weekly cancer-focused educational material. Cohort 2 was given the same content, with the addition of an emailed weekly message providing participants with a summary of their exercise history, sleep duration, and an overview of their reported symptom scores. Cohort 3 received the same content as cohort 2 plus regular personalized coaching email messages from an accredited exercise physiologist. These messages focused on a range of behavioral change strategies, including motivational, discussed fatigue and pain scores, and provided feedback on and goal targets for step counts. Study procedures are shown in Figure 1.

Following the 10-week intervention, the evaluation of participant use of and engagement with the Web portal was supplemented by in-depth qualitative interviews. A thematic analysis approach was taken.

Figure 1. Study procedures.



## Ethics, Consent, and Permissions

All procedures performed in this study were in accordance with the ethical standards of the institutional and national research committee, and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Permission to conduct this study was granted by the Royal Prince Alfred Hospital Human Research and Ethics Committee (X16-0051). All participants provided written informed consent.

### *Consent to Publish*

All individual participants included in the study provided consent to publish.

## Participant Recruitment

Participants of the substudy were recruited from our previously reported larger cohort study [12]. All participants were either currently undergoing treatment for their cancer, or had completed treatment within the last 6 months, and were recruited from a single cancer care center located in Sydney, Australia. Participants were purposively sampled from across each of the 3 study cohorts, and each of the participants had completed the intervention before participating. Each potential participant was approached by telephone by one of the research team members seeking consent for a semistructured interview. For those consenting, time for a telephone interview was mutually agreed and booked.

## Procedure

Interviews were completed from July to September 2017. Individual semistructured interviews were conducted once only,

via telephone from a private meeting room by a PhD-qualified female, translational health researcher with experience in qualitative methods (AJ). The interviewer was not known to participants and not involved in the larger feasibility study. Participants were informed that the discussion was being audio-recorded and verbal confirmation of their consent for this was obtained. Only the participant and researcher were present during interviews. Field notes were recorded during interviews.

Participants were asked to explore their experiences of using the Web portal, using an activity monitor, and their perception of the personalized coaching messages if they were in cohort 3. An overview of the semistructured interview guide is provided in [Textbox 1](#). Questions were intended to guide the conversation, rather than be prescriptive. The interviewer was responsive to participant comments and tailored questions and probes to draw out the informative comments from participants.

Audio files were transcribed verbatim by a professional transcribing service. Accuracy of transcriptions was checked by 1 of 2 authors (MM and AJ) before each being analyzed. Participants were not sent transcripts for comment and did not give feedback on the research findings. Recruitment of participants continued until data saturation was achieved [16]. To limit the possibility of introducing bias, each author had independently reviewed the transcripts and agreed data saturation had been achieved. Those interviews already booked were completed to confirm no new themes were identified. The COnsolidated criteria for REporting Qualitative research checklist is given in [Multimedia Appendix 1](#).

**Textbox 1.** Interview framework.*Initial exploration*

- Could you please tell me about your previous use of technology (eg, applications and fitness trackers)?
- Could you tell me about how you found using the Web portal?
- Usability of the Web portal
- Use and usefulness of the accelerometer
- Quality and usefulness of seeing and inputting your data
- Did you utilize the educational part of the Web portal (eg, nutrition information)?

*For people getting personalized messaging*

- How did you find the weekly personalized messaging/coaching you received?
- Do you recall any specific messages that you received?
- Did the messaging help to motivate you?

*For people getting summative messaging*

- How did you find the weekly summative messaging you received?
- Was the data useful?
- Did the messaging help to motivate you?

*Advice*

- Are there things that could have been done differently that may have improved your experience?
- What would you recommend to other people using the Web portal?
- Will you continue to use the portal?
- Yes. Why?
- No. Why not?

*Future use*

- Explore the concept of gamification—individual and between participants.
- Positives and negatives
- Discuss the use of video calls with health professionals as part of the portal.
- Positives and negatives
- Would you pay to use the Web portal?
- Potential business model

**Data Analysis**

We analyzed the interview data thematically [17] using a framework approach [18]. Initially, the interviews were coded line by line for descriptive experiences (MM, male; MPH, health researcher, and exercise physiology clinician). In all, 3 transcripts were distributed for individual review and independent initial code generation among the team (MM; HD, female, PhD, behavioral scientist; and AJ). MM and HD were not present for the participant interviews. After consultation and cross-coding, the initial codes were expanded facilitating development of a coding tree. Data were charted using Microsoft Excel version 16.5 [19]. Attention was paid to contrasting differences in experience between the 3 study cohorts. We then compared and contrasted emergent themes until we were confident that we had captured the predominant thoughts and perspectives evident in the interviews. As a research team, we

refined these themes for clarity and completeness. To maintain data rigor and independent coding, consensus, when disagreements arose, was achieved through group discussion, data saturation was determined independently and agreed by researchers, and independent and comparative coding was undertaken.

**Results**

A total of 49 participants (median age 54 years, range 28-79, 22% [11/49] male) took part in the feasibility study across the 3 cohorts. Of these, 17 completed semistructured interviews via telephone (median age 57 years, range 30-79, 35% [6/17] male). The median length of interview was 19 min (range 13-26 min). Demographic details of each participant are presented in [Table 1](#).

Themes were iteratively developed from exploratory categories. (3) future developments. Several subthemes underpinned each We purposefully explored 3 areas related to the Web portal. of these 3 overarching themes and are detailed in [Textbox 2](#). These areas were (1) engagement, (2) design and usability, and

**Table 1.** Individual interviewee demographics.

Cohort: participant number <sup>a,b,c</sup>	Age (years)	Sex	Cancer type classification	Stage of treatment (active therapy or survivorship)
1.1	55	F	Breast	Survivorship
1.2	42	F	Breast	Survivorship
1.3	54	M	Melanoma	Active
1.4	75	F	Colorectal	Survivorship
1.5	79	M	Prostate	Survivorship
1.6	59	F	Hematological	Active
1.7	58	F	Breast	Survivorship
2.1	30	M	Hematological	Active
2.2	52	F	Hematological	Active
2.3	60	F	Breast	Survivorship
2.4	61	F	Breast	Active
2.5	57	M	Head and neck	Survivorship
3.1	40	M	Colorectal	Active
3.2	73	F	Breast	Survivorship
3.3	59	F	Breast	Survivorship
3.4	51	M	Hematological	Survivorship
3.5	54	F	Lung	Survivorship

<sup>a</sup>Cohort 1: portal/device only.

<sup>b</sup>Cohort 2: additional automated education.

<sup>c</sup>Cohort 3: additional tailored coaching messaging.

**Textbox 2.** Overview of qualitative themes.

- Engagement through intervention
  - Facilitated behavior change
  - Device wearability and engagement
  - Engagement with intervention
  - Impact of personalized messaging
  - Personal factors impacting on engagement
  - Technical issues impacting engagement
- Web portal
  - Patterns of use and engagement
  - Ease of use
  - Educational content
- Future development
  - Gamification
  - Addition of telehealth consultations
  - Developing a business model



## Engagement Through Intervention

The engagement theme encompassed aspects of the Web portal, the wearable device, personalized messaging, and a range of other factors impacting behavior. Many participants, particularly those in cohorts 2 and 3, indicated that the intervention facilitated positive behavior change:

*I really liked it. I found that just... It gave me a bit more motivation to actually increase my activity level. I did find that I was checking my wristband a lot to see if I'd met my daily activity goal and when I didn't I felt like... Not a sense of... Not failure but just like, "Aw, I didn't meet my goal. I have to make sure I do extra tomorrow," kind of thing. It was just really, really motivating. I felt like I did definitely increase my exercise over that time. [Participant 3.1]*

*So that was sort of an on-going, that's what kept me honest. [Participant 3.5]*

*Some days you might be more bound to your desk or at home not doing so much, and it's a good tool to prompt you to change your habits, and get up... [Participant 1.6]*

The activity tracker (Misfit Shine) provided to most participants at commencement of the intervention was generally well liked. Participant feedback suggests the usability and engagement of this device to be high across each of the 3 cohorts:

*Yes. I absolutely love the thing that you wear on your arm. I'm just elated. I think it's really motivating, and I really enjoyed having that. [Participant 1.3]*

*Absolutely, absolutely I loved it. It was really good to see exactly what it took to get to my goal each day and I love it. To the point I'm going to get another one and it's going to be a part of my life to have a fitness tracker now. [Participant 3.3]*

Overall, participants in all cohorts were generally positive about their involvement, indicating a positive engagement with the intervention as a whole:

*I just thought it was a very constructive and positive experience... it was really helpful in terms of making a progressive recovery. [Participant 2.4]*

*It was really good to be part of it, it really helped me through my chemo so I was really grateful. [Participant 3.1]*

Those participants in cohort 3 who received personalized messaging typically revealed that the use of personalized coaching messaging was highly acceptable and provided additional motivation to help them succeed with goal attainment and increasing physical activity levels:

*...and it actually made me happy. It gave me a sense of achievement, especially when the EP would send the message saying, "Wow, you've matched your goals. Well done." I felt a lot of pride in myself. [Participant 3.1]*

*It made me just push myself and even on days when I didn't want to walk I thought no my steps were down*

*and I should get out there and go for a walk and so on. [Participant 3.3]*

They contrasted with cohorts 1 and 2, where participants indicated a need and preference for increase in health professional contact during the intervention period:

*...but if someone motivated me to say, "Would you like to come in and have a look at that app again and I'll show you what it does. And let's see how you're going with it," then that might have...I might have engaged with it a bit more...or at all. [Participant 1.3]*

*...some interaction and discussion with the individual (researcher), I would think that that would improve uptake, it would also encourage you to think about it a bit more. [Participant 2.6]*

*And I guess that I don't interact with anybody or get anything but a lot of information that I already know doesn't add much to that undertaking. If it was a more interactive component maybe or something. [Participant 1.1]*

Personal factors appeared to have an impact on engagement. The intervention gave 1 participant an opportunity to reassure their family about the safety of their exercise plan:

*They worried about me overdoing it, that sort of thing. And so I could go back to them and say, "Look, I've spoken to the exercise physiologists at the hospital and they say this is okay..." I think for them, they were reassured, as far as they're concerned. [Participant 3.2]*

A small subset of participants had technical issues with the perceived accuracy of their device; in particular, they felt the sleep tracking was inaccurate. It appeared to impact their use of the Web portal and decreased their engagement in remote monitoring:

*I think the sleep is inaccurate, I think definitely the exercise and the physical activity was probably much more accurate. [Participant 3.5]*

*So I don't think the data is accurate, so I didn't bother. [Participant 2.3]*

## Web Portal

Focusing on the Web portals' design and usability, we identified 3 additional themes, as described in [Textbox 2](#). They included patterns of use and engagement. Reported use varied among participants, from a daily habit to less frequent interactions. Overall, participants in cohorts 2 and 3 reported engaging more with the Web portal than those in cohort 1:

*I used it daily to do the updates. It's really easy to use, it's to the point and I thought it was really good the way it gathers information to the quantities of data. [Participant 2.4]*

*Weekly, just weekly. I went in, I put my data in daily and did my weekly update, and then I went into and also read the articles weekly. [Participant 2.2]*

Participants in cohort 1, who had no messaging or health professional interactions, reported engaging with logging their

symptoms and viewing content early in the program. However, this was more likely to decrease over time when compared with cohorts 2 and 3:

*...and I did go onto the portal a few times, but I haven't been on it, I'd say, the last couple of weeks.*  
[Participant 1.6]

Reported ease of use of the Web portal was also seen to be impacted with less health professional interaction. A number of participants in cohort 1 who had no additional interaction following the goal attainment session reported more technological barriers:

*I could have done with a few more lessons in how it worked, because I know how to collect the steps and how to log on. But maybe another session in just following up on showing me ...So I feel like if someone had said, "Would you like [me to]...Check on how you're going with it and show you some other things that are available," that probably would help.*  
[Participant 1.3]

Cohorts 2 and 3 had access to a curated selection of Web portal educational content which was also sent in weekly emails, focused on supportive cancer care-specific topics such as sleep, fatigue, and nutrition. It included written articles, video content, and links to government-supported information. Participants typically found the Web portal educational content to be acceptable:

*I like to be able to look at and research more information and have different resources available. So I did find that quite useful.* [Participant 2.6]

*I thought it was really good, the information was presented in a glaring manner.* [Participant 2.4]

In the main study, the percentage of participants who opened a link in their educational email averaged 60% to 70% each week. It ranged from 59% to 94% depending on the week and topic area [12]. When probed in interviews, we identified a need to tailor content to the stage of participants' cancer treatment:

*Some of the stuff I might have been interested in two and a half years ago, but it's not so relevant to me now.* [Participant 3.5]

*If I was sort of in the middle of cancer treatments, like active cancer treatment, I probably would have found the information more helpful.* [Participant 2.2]

Respondents found the educational content too broad and basic; they expressed a preference for more specific, detailed information:

*I looked at it once or twice, but I just found it a bit basic.* [Participant 2.5]

*A lot what was written was things that I had read already. That's why I wasn't finding a whole lot of new information for me.* [Participant 2.2]

## Future Developments

The third major theme was related to future developments of the Web portal, with 3 subthemes identified. Results indicated variability in preferences and that individual tailoring is required

across the care continuum. There were some positive responses to gamification:

*I was always really, really interested to know how I was doing compared to the other patients. Not necessarily specifically but just like, "You're in the top 5% of the patients," or something like that. That would have been really, really... Even more motivating to know how well I was doing in general, compared to the other people for sure.* [Participant 3.2]

While others had concerns about the impact of gamification on individual sense of achievement and ongoing motivation:

*Possibly not because I've problems with walking long distances, and it would perhaps make me feel more self-conscious that I couldn't actually achieve what other people achieve.* [Participant 1.6]

Several participants welcomed the possibility of commercialization of such an intervention, although engagement is likely to be dependent on pricing:

*I don't think anyone really likes to pay, but depending on how much it was, I would.* [Participant 3.4]

*I'm not sure because I am, as I said, because I'm at a different stage of my experience with cancer that, had I'd been in the middle of it, I would probably feel differently. At this stage, probably not.* [Participant 2.5]

We also discussed the use of video calls as a supplement to the program. Again, there was a mixed response to this concept, and engagement would likely vary across the population:

*Absolutely actually...Particularly questions on fitness and questions on nutrition, yeah. Because they're the hard ones to get, right? There's not enough of them at the hospital, to be honest.* [Participant 2.3]

*Probably not. Sounds a bit too much like work.* [Participant 1.6]

## Discussion

### Principal Findings

The main findings of this study are that (1) participants reported increased health professional contact facilitated greater engagement in the Web portal, (2) participants perceived benefit in using the provided activity tracker (Misfit Shine), and (3) that education, support, and feedback mechanisms need to be specifically tailored to each individual. These findings support our earlier findings around the feasibility and acceptability of a Web portal and activity tracking in a mixed population of cancer survivors [12]. Here our participants' experiences have provided novel, in-depth perspectives on the usability of a clinician-patient Web portal.

One of our key themes indicates that oncology health support programs and systems should be tailored using a market fragmentation approach, a concept that there is diversity within all markets and each market is composed of multiple segments (eg, individual patients), reflecting different needs, behaviors,

and responses to engagement within users [20]. This approach in cancer care enables health support programs and systems to be tailored to different needs and preferences of individual patients and survivors. Previous digital health interventions have typically not done this. Therefore, high rates of dropouts and low engagement are the results.

Supporting our quantitative data, qualitative results indicated a contrast among the 3 cohorts and their levels of engagement with the Web portal. It supports the conclusion that increasing health professional contact led to an increase in reported engagement. The study highlights the importance of personalized messaging and tailoring information to increase participant perceptions of the value of the intervention.

This study highlighted the key theme of matching an individual with an appropriate feedback strategy when implementing these types of interventions, which includes the use of personalized messaging. There has been a recent interest, and promising results, in the use of automated messaging, such as those sent through SMS, to drive health behavior change within certain populations, such as for people with diabetes and depression [21,22]. Although there is potential for automated interventions be delivered to 1 patient subgroup with positive effect, others may best respond to personalized messaging sent by a health professional or health coach. This approach to targeting population via tailored messaging requires more research to be used effectively in practice.

This study also emphasized the critical need for tailored educational material congruent with individual's health literacy level, prior health knowledge, treatment status, and prognosis. This finding is supported by a recent systematic review across multiple chronic conditions [23], which concluded that there was a moderate level of evidence supporting tailoring of communication strategies to patient health literacy. Several other studies have reported positive results when tailoring communications to different stages of the cancer care trajectory, as there are evolving information needs across the cancer care trajectory with those needs being quite distinct in active treatment compared with survivorship phases of care [24-26]. It is noted that our study included both participants undergoing intensive cancer treatment and those in the survivorship stage. They need to be differentiated.

Although the intervention participants took part in did not include any concepts of gamification, interview questions explored whether this would have any additional benefit. Gamification focuses on applying game mechanics to nongame

contexts to improve engagement and support lasting change [27]. There were mixed responses to the role of gamification in this study ranging from enthusiastic support through to concerns that it would negatively impact those who were unable to *compete* fully because of physical side effects of treatment. Previous *corporate* health and wellness offerings have included such concepts as challenges, points, leader boards, and rewards mechanisms [28-30]. These concepts are emerging in the health care field [31,32]; however, such interventions may have challenges adapting to the specific needs of patients during intensive cancer therapy, or who have recently completed such treatment. There may also be potential concerns regarding privacy legislation [27]. This concept requires further investigation.

If there are promising results, digital health interventions need to consider scalability, and how they could be widely enabled within a health system. In the case of this intervention, patient access to Web portals, enhanced with components such as personalized coaching messaging, has the potential for broader dissemination.

### Limitations

The study has some limitations. As a nested substudy, we recruited only a subset of those participants from our larger feasibility study, and their experience may not be representative of all study participants or the broader cancer population. We used data saturation to determine when to cease recruitment to the study, and this may have introduced a bias through the interpretation of interview data by the research team. Given the predominance of women with breast cancer in our study, the results may be biased by their reported perceptions over other tumor groups. Participants were largely white living in metropolitan areas, which does not provide insight into the needs of culturally and linguistically diverse or regional and rural populations.

### Conclusions

With an increasing interest in, and use of, digital interventions in supportive cancer care, there is a need to understand patient experience of such technology. Our participants reported a mostly positive experience of using a Web portal and activity monitor. It was also clear that personalized messaging positively impacted on participants' health behaviors. Future studies should focus more on design of interventions, ensuring appropriate tailoring of information and personalization of behavioral support messaging.

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### Acknowledgments

The authors thank the participants who shared their experiences for the benefit of others.

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### Conflicts of Interest

None declared.

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Multimedia Appendix 1

COnsolidated criteria for REporting Qualitative studies (COREQ): 32-item checklist.

[PDF File (Adobe PDF File), 365 KB - cancer\_v5i2e15539\_app1.pdf ]

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Original Paper

# Complementary and Alternative Medicine in Patients With Breast Cancer: Exploratory Study of Social Network Forum Data

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## Abstract

**Background:** Patients and health care professionals are becoming increasingly preoccupied in complementary and alternative medicine (CAM) that can also be called nonpharmacological interventions (NPIs). In just a few years, this supportive care has gone from solutions aimed at improving the quality of life to solutions intended to reduce symptoms, supplement oncological treatments, and prevent recurrences. Digital social networks are a major vector for disseminating these practices that are not always disclosed to doctors by patients. An exploration of the content of exchanges on social networks by patients suffering from breast cancer can help to better identify the extent and diversity of these practices.

**Objective:** This study aimed to explore the interest of patients with breast cancer in CAM from posts published in health forums and French-language social media groups.

**Methods:** The retrospective study was based on a French database of 2 forums and 4 Facebook groups between June 3, 2006, and November 17, 2015. The extracted, anonymized, and compiled data (264,249 posts) were analyzed according to the occurrences associated with the NPI categories and NPI subcategories, their synonyms, and their related terms.

**Results:** The results showed that patients with breast cancer use mainly physical (37.6%) and nutritional (31.3%) interventions. Herbal medicine is a subcategory that was cited frequently. However, the patients did not mention digital interventions.

**Conclusions:** This exploratory study of the main French forums and discussion groups indicates a significant interest in CAM during and after treatments for breast cancer, with primarily physical and nutritional interventions complementing approved treatments. This study highlights the importance of accurate information (vs fake medicine), prescription and monitoring of these interventions, and the mediating role that health professionals must play in this regard.

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**KEYWORDS**

complementary and alternative medicine (CAM); nonpharmacological interventions; cancer; social network; forum; patient

## Introduction

### Background

Supportive care complements approved and prescribed treatments of cancer, predominantly, nonpharmacological methods called as nonpharmacological interventions (NPIs) [1] or, more imprecisely, complementary and alternative medicine (CAM). Nowadays, patients are interested in these health solutions aimed to improve quality of life, reduce symptoms, and supplement treatments. Their uses are beyond the control and/or prescription of health professionals. Supply and demand is accelerated, especially on the internet and social networks [2]. These digital platforms extend NPIs to unknown and potentially dangerous and erratic practices, such as plants from faraway countries, electronic commerce of food supplements without manufacturing control, traditional medicines, empirically selected practices, innovative startup solutions that do not have enough time or means to carry out proper clinical trials, and hidden sectarian practices. Between 30% and 40% and between 15% and 75% of the general population in the United States and Europe, respectively, use CAM [3]. The use of CAM in oncology has been increasing for the past 10 years, in particular, to reduce the side effects of chemotherapy, radiotherapy, and surgery [4]. The use varies between 18% and 83% depending on the measurement method, type of cancers, and their definition. In breast cancer, 72% of women would use it [5]. More than half would not mention them to their oncologist, contributing to the difficulty to obtain accurate frequencies of use [6,7]. Patients may argue that their lack of mention to their oncologist or general practitioner stems from their providers' lack of question on the topic, their lack of interest, an anticipation of disapproval, or their presumed inability to help them [8]. Patients mentioned several reasons, such as the lack of information on NPIs for the management of cancers (61% of cases), the lack of question from their oncologist (60%), the thought that this does not concern the doctor (31%), the fact that their doctor might not understand the situation (20%), the fact that their doctor would disapprove (14%), and the risk that their doctor would no longer take care of them (2%) [9]. These untolds carry risks during and after cancer treatments, with NPIs potentially generating adverse effects, deleterious interactions, and noncompliance with treatments [10,11].

One way to better understand this opaque use of CAM during cancer treatment is to explore patients' views through specialized social networks. In 2018, 3 billion people used a social network, that is, 40% of the world's population [12,13]. About 20% of discussions on these networks are related to health [14]. Patients find a space for open dialog among peers. These platforms also allow an exchange and appropriation of medical information, in particular, to seek answers when they have not been provided by a health professional [15-17]. This need is particularly pervasive in patients with cancer treated with complex and combined therapies. About 35% of health focus groups and forums are dedicated to cancer and sharing experiences with cancer [14,18]. Approximately 50,000 new cases of breast cancer are diagnosed every year in France [19,20]. Therapies and remission rates have progressed

considerably in this field, improving patients' outcomes and minimizing treatment side effects. The major national cancer organizations and associations support the creation of patient discussion forums to promote mutual help and sharing of experiences [21]. These forums have become a valuable source of information on NPI uses.

### Objectives

The primary objective of this exploratory study was to identify and quantify CAM-related words used from posts published on health forums and social media groups of patients with cancer patients. The secondary objective was to distinguish the words among the following 5 categories of NPIs: digital, nutritional, psychological, physical, and other.

## Methods

### Design

We conducted a retrospective frequency analysis of the words used in NPIs from a database compiled from internet-based French-language forums and discussion groups of patients treated or followed for breast cancer. These specialized social networks consisted of 2 patient forums (*impatientes* and *breast cancer*), 4 Facebook discussion groups (*Breast cancer; Pink October 2014; Breast cancer, let's talk about it; and Breast-cancer*), and 4 Facebook pages (*Breast cancer a merciless war, Breast cancer talk group, Breast cancer, and Like-breast cancer*). The French National Cancer Institute recommended these forums to patients.

The 264,249 posts published in these forums and Facebook pages (without additional information for each post, such as the number of views, comments, shares, or likes) were collected and anonymized with the agreement of the French nonprofit breast cancer patient organization. All surnames, first names, pseudonyms, and location information (eg, city, region, and facility name) were replaced with generic labels. The use of these compiled retrospective data did not require authorization from an ethics committee or a personal protection committee in accordance with French laws and regulations.

Data collection was performed at the University of Montpellier in France. All local institutional review boards approved the protocol, and the Independent Ethics Committee of Collège National des Généralistes Enseignants (Avis N° 110719118) accepted the protocol. The Ethics Committee of the College of Teaching General Practitioners (IRB No. IRB00010804) has ruled that, under the French law, the research "Complementary and Alternative Medicine in Patients with Breast Cancer: An Exploratory Study of Social Network Forums Data" was carried out in accordance with national regulations.

### Population

According to a source dated April 2018 [22], the *Impatientes* forum counted 10,576 members who have provided their birthdate (6% aged below 35 years, 18% aged 35-45 years, 32% aged 46-55 years, 28% aged 56-65 years, and 15% aged above 65 years). We used the 160,890 posts from June 3, 2006, to November 17, 2015, of 5053 participants to disseminate information about breast cancer prevention, detection, and care.

The association had created a Facebook page that was followed by 720,261 people [23]. We used 16,927 posts from an unknown number of participants from 2006 to 2015.

In April 2018, 1713 people subscribed to the Facebook page *Breast cancer, a merciless war* [24]. We used the 86,432 posts from January 10, 2010, to September 28, 2015, of 1044 participants.

### Data Analysis

All NPI terms were searched in the compiled database of 264,249 posts. These queries were made from the ontology of

NPIs provided by the academic and collaborative *Plateforme CEPS* (Figure 1) [1,25]. Each query considered singular/plural, abbreviations and misspellings, and words with and without dashes (eg, *non-pharmacological* and *non pharmacological*) as equivalent to the ontology's featured word. The method consists of identifying and counting the NPI terms mentioned in the social network posts. We conducted 2 successive descriptive frequency analyses: (1) an analysis of the occurrences of NPI categories and their synonyms (Figure 1) and (2) a subcategory analysis with NPI terms, their synonyms, and their related terms (eg, ingredient, technique, method, and profession).

**Figure 1.** Nonpharmacological intervention ontology terms without all their related synonyms.

Psychological Health Interventions	Physical Health Interventions	Nutritional Health Interventions	Digital Health Interventions	Other Health NP Interventions
Art Therapy Health Education Psychotherapy Zootherapy	Physical Activity Hortitherapy Physiotherapy Manual Therapy Thermalism	Dietary Supplements Nutritional Therapy	eHealth Devices Therapeutic Games Virtual Reality Therapy	Ergonomic tools Phytotherapy Cosmetic Therapy Wave Therapy Lithotherapy

## Results

### Nonpharmacological Interventions' Categories and Synonyms

Within our dataset, patients referred to an NPI category 14,185 times, 84.51% (11962/14195) from the *Impatientes* forum,

8.57% (1217/14195) from the *Breast cancer* forum, and 6.92% (986/14195) from Facebook groups and pages (Table 1). The study population mainly referred to physical and nutritional interventions and others in similar proportions between forums and Facebook groups/pages. The term *NPI* (abbreviated or not) was rarely used by patients (20 occurrences in total), whereas the term *CAM* was never used.

**Table 1.** Occurrences of nonpharmacological intervention categories in 264,249 published posts.

Categories	Total occurrences, n <sup>a</sup> (%)	<i>Impatientes</i> forum, n1 <sup>b</sup> (%)	<i>Breast cancer</i> forum, n2 <sup>c</sup> (%)	Facebook group/page, n3 <sup>d</sup> (%)
Physical	5197 (36.64)	4423 (36.90)	394 (32.40)	380 (38.7)
Nutritional	4437 (31.28)	3827 (31.93)	403 (33.14)	207 (21.1)
Psychological	636 (4.48)	496 (4.14)	54 (4.44)	86 (8.7)
Digital	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.0)
Others	3915 (27.50)	3241 (27.03)	365 (30.02)	309 (31.5)
Total	14,185 (100.00)	11,987 (100.00)	1216 (100.00)	982 (100.0)

<sup>a</sup>n refers to the entire population under study.

<sup>b</sup>n1 refers the entire population of forum *impatientes* under study.

<sup>c</sup>n2 refers the entire population of forum *breast cancer* under study.

<sup>d</sup>n3 refers the entire population of Facebook group under study.



### Nonpharmacological Interventions' Subcategories, Synonyms, and Related Terms

The total number of subcategories and related terms is 13,084. No mention was made in the database of terms related to digital health intervention (eg, serious game, health device, connected health tool, app, digital tool, and virtual coach). The subcategories of physical health interventions mentioned were physical activity programs (83.5%) and manual therapies (15.4%) and physiotherapy (1.1%) as shown in Table 2. The 3 physical interventions most commonly mentioned were exercise (36.4%), acupuncture (32.4%), and yoga (16.0%).

Table 3 details cited health nutrition interventions. Of the 4437 occurrences obtained, dietary supplements were most prevalent (77.9%) compared with nutritional therapies (22.1%). The most cited health nutrition interventions were vitamins (39.3%), honey (12.2%), iron (10.7%), and grapefruit (6.7%).

Table 4 presents the results of the subcategories of psychological health interventions. Psychotherapies were predominant (97.0%). The most used term was sophrology (34%).

Regarding other health interventions, the most popular was herbal medicine in forums and Facebook solutions (Table 5).

**Table 2.** Repartition of occurrences for the physical health intervention category.

Subcategories	Total occurrences (number of times the occurrence is cited)	<i>Impatientes</i> forum	<i>Breast cancer</i> forum	Facebook	Related terms <sup>a</sup>
Physical activity programs	3253 (+1087) <sup>a</sup>	2769 (+940)	228 (+84)	256 (+63)	Shiatsu, yoga, tai chi, body building, Pilates, hatha yoga, and Iyengar yoga
Horticultural therapies	0	0	0	0	— <sup>b</sup>
Physiotherapies	7 (+52)	5 (+39)	0 (+7)	2 (+6)	Speech therapy
Manual therapies	4 (+796)	4 (+667)	0 (+75)	0 (+54)	Acupuncture, acupressing, osteopathy, reflexology, auriculotherapy, and chiropraxy
Thermal cares	0	0	0	0	—

<sup>a</sup>The number of occurrences of related terms to the subcategory physical activity programs, not as a synonym (eg, exercise) but as a related term (eg, Pilates).

<sup>b</sup>Not applicable (no one mentioned).

**Table 3.** Repartition of occurrences for the nutritional health intervention category.

Subcategories	Total occurrence (number of times the occurrence is cited)	<i>Impatientes</i> forum	<i>Breast cancer</i> forum	Facebook	Related terms
Food supplements	488 (+2970)	413 (+2699)	53 (+150)	22 (+121)	Alpha linolenic acid, iron, gamma linolenic acid, amino acids, magnesium, minerals, niacin, ascorbic acid, palmitic acid, creatine, fish oil, biotin, calcium, bioflavin, vitamin (A, C, B, B1, B2, B3, B6, B12, D, D3, and E), multivitamin, and folic acid
Nutritional diets	2 (+977)	2 (+713)	0 (+200)	0 (+64)	Dukan diet, fasting, and micronutrition

**Table 4.** Repartition of occurrences for the psychological health intervention category.

Subcategories	Total occurrences (number of times the occurrence is cited)	<i>Impatientes</i> forum	<i>Breast cancer</i> forum	Facebook	Related terms
Health education programs	1 (+0)	1 (+0)	0 (+0)	0 (+0)	Tobacco cessation
Psychotherapies	59 (+561)	54 (+431)	2 (+51)	3 (+79)	Hypnosis, hypnotherapy, self-hypnosis, autosuggestion, sophrology, support group, and mindfulness-based stress reduction
Art therapies	2 (+1)	1 (+0)	0 (+0)	1 (+0)	Musicotherapy
Zootherapies	12 (+0)	9 (+0)	0 (+1)	3 (+0)	— <sup>a</sup>

<sup>a</sup>Not applicable.

**Table 5.** Repartition of occurrences for the other nonpharmacological intervention category.

Subcategories	Total occurrence (number of times the occurrence is cited)	<i>Impatientes</i> forum	<i>Breast cancer</i> forum	Facebook	Related terms
Cosmetic therapies	0 (+481)	0 (+289)	0 (+150)	0 (+42)	Wig and makeup
Wave therapies	12 (+1)	1 (+0)	0 (+0)	1 (+0)	Chromotherapy, light therapy, quantum medicine, electrotherapy, and magnets
Phytotherapies	83 (+2218)	79 (+1888)	1 (+146)	3 (+184)	Aloe vera, aromatherapy, belladonna, calendula, chamomile, cinnamon, milk thistle, clove, echinacea, eucalyptus, feverfew, devil's claws, mistletoe, herbs, hops, linseed oils, essential oils, hypericum, kava, lavender, alfalfa, marijuana, peppermint, St. John's wort, blueberry, passionflower, dandelion, elderberry, tea, red clover, valerian, cranberry, pomegranate, bitter orange, wild yam, grapefruit, cocoa, and noni
Lithotherapies	1 (+16)	1 (+15)	0 (+0)	0 (+1)	Stone
Ergonomic tools	0 (+0)	0 (+0)	0 (+0)	0 (+0)	— <sup>a</sup>

<sup>a</sup>Not applicable.

## Discussion

### Principal Findings

Our study exploring a large dataset from social networks highlights the attractiveness of NPIs for patients with breast cancer. The results from conversations in 2 forums and 4 Facebook discussion groups and pages recommended by the French National Cancer Institute indicated that 27,279 words were related to NPIs in the 264,249 posts analyzed. NPIs are clearly a topic of concern for patients with a generally similar interest in the categories between forums and Facebook sources. Patients seek information about the best use of NPIs and use these NPIs. The study supports the results of a survey conducted in 2005 on CAM by using a structured questionnaire with an average of 35.9% of a sample of 956 European patients [7]. The European study had identified 33 CAM [7], whereas this study identified 101 CAM. This figure could have been even more extensive if the patients had precisely mentioned the method rather than the profession (eg, osteopathy, acupuncture, chiropractic, speech therapy, sophrology, music therapy, light therapy, and aromatherapy) or the vector (eg, minerals and pebbles). Our study thus confirms the ability of social networks to address more deeply and broadly the NPI/CAM spectrum compared with a questionnaire survey. Indeed, the questionnaire may hinder patients from revealing their real uses and/or concerns about practices decried by some health authorities (eg, cannabis). Questionnaires restrict responses to those designed in advance by researchers. They suggest inappropriate contextual and temporal conditions for dealing with topics in depth. They may limit the representativeness of the patients interviewed, whereas the use of NPIs is known to vary according to age, gender, socioeconomic level, residence, and country [7,26]. This analysis of real-life postings makes it possible to point out original practices. If a social network reinforces personal convictions, it offers patients the opportunity to discover new practices consistent with these beliefs.

This study indicates that the words used by health professionals and researchers to describe all nonpharmacological solutions such as *NPI* or *CAM* are very rarely used by patients with breast cancer. The vocabulary used by the patients is pragmatically focused at the level of the methods of care and not at the level of their categories. One aim of digital social networks is to answer usage questions of a vast and opaque field mixing methods (eg, hatha yoga), ingredients (eg, cinnamon), disciplines (eg, physiotherapy), skills (eg, profound breath), and alternative dangerous medicines (eg, quantic medicine). Our descriptive study reveals the diversity of NPIs used by French or at least Francophone patients during breast cancer treatment and recurrence prevention. It reflects a wide range of health goals. Biologically, patients seek these nonpharmacological solutions for an improvement of the efficacy of their treatments (eg, compliance with scheduled doses of chemotherapy, prevention of cachexia, and prevention of fat gain) and a reduction of treatment side effects (eg, decreased nausea and pain or fatigue) [27]. At the psychobehavioral level, they look to reduce anxiodepressive signs (eg, self-esteem and/or body image trouble) [26,28], change health behaviors (eg, smoking cessation), and improve their quality of life.

The predominant categories are physical and nutritional interventions. These care strategies begin to be integrated into support care departments of French cancer hospitals. The physical activity subcategory is predominant and is consistent with recent mechanistic studies [29,30], meta-analyses [31,32], and authorities' recommendations [33,34]. Although clinical trials have shown benefits of a physical activity program on quality of life and treatments side effects (eg, fatigue, depressive symptoms, and physical condition), recent studies suggest effects on the reduction of tumor growth rate [35] and the prevention of recurrence in patients aged younger than 40 years [36]. Our results testify to the capacity of social networks to convey scientific and medical messages, the subsidiary question, which our data cannot answer, being to know the modalities of practice (eg, intensity, frequency, and duration). The subcategory manual therapies are present, in particular, for practices known for their

pain-relieving effect (eg, acupuncture). It should be noted that there is no vocabulary associated with spa treatments in a country known for offering many interventions reimbursed by national health insurance.

Nutritional health interventions, the second most frequently cited NPI category, have been studied by observational cohorts and pilot trials, suggesting their efficacy in curative breast cancer treatments [35,36]. The goal of maintaining a normal weight through a diet is a factor of good prognosis [35], whereas weight gain after the diagnosis of breast cancer is associated with a higher mortality rate, further increased in case of a weight gain of 10% or more [37]. If food supplements are debated in the literature [38], patients have a particular interest in them based on the frequency of citation.

A common subcategory in the other NPI category is herbal medicine. Herbal remedies are popular among cancer patients as indicated by surveys [7], despite persistent scientific doubts about their toxicity, their risk of interaction with chemotherapy, and their efficacy in reducing symptoms or acting on the tumor [39]. Another subcategory is also mentioned to a lesser extent in the category of psychological health interventions, psychotherapies. Some are beginning to be advocated in the curative pathways of patients with breast cancer to relieve anxiety symptoms, depressive symptoms, and mood disorders [40].

In contrast to our literature-based assumptions [13,15], digital health interventions were not mentioned in the studied forums and groups. Is it because of old data (before 2016) or a lack of interest of patients nevertheless sensitized to digital solutions by their participation in a social network? The results indicate that French-speaking patients with breast cancer do not care or wonder about serious games, virtual reality, and connected objects. They may not be aware of their effect on health. The generalization of oral chemotherapy with serious risks in case of misuse and the familiarization of health professionals with these solutions will undoubtedly increase the use of these digital systems (eg, pillboxes and a specific informational app). This justifies further longitudinal and prospective studies.

This study indicates the value of forums and focus groups in supporting patients during cancer and postcancer treatments [41]. At the individual level, they have a function of exchanging information, sharing experiences, recommending healthy behavior, and providing social support [21,42]. This mutual support among peers living with the same medical situation is a factor in improving quality of life [43]. Forums and discussion groups are easily and quickly accessible. They provide detailed information that is personalized, educational (*patient language*, drawings, and videos), accessible everywhere, updated, voluminous, anonymous, and free. They are a source of strategy for obtaining support to help sustain change in health behavior [44] and to think about how to collaborate with health professionals in a disease so elusive to the naked eye. This empowerment [42] facilitates the personalization of care toward integrated solutions. Patients seek to make sense of their disease to improve their health, to maximize their chances of healing/survival without recurrence/prolonging period without recurrence, to restore their femininity, and to improve their

quality of life. It is legitimate for patients to seek the best solutions for treatment through all means available to them.

At the collective level, forums and discussion groups reinforce the sense of belonging to a community, access to rights, identity claims, and the desire to contribute to the improvement of care practices. As patients wonder about their care by sharing experiences through social media, they are no longer *patients* but actors in collaboration with their caregivers and community. They seek to help their neighbor. In this context, it is significant to note the development of the status of *expert patient*. Some engage in university courses to go beyond the mere experience of disease, stigma, and ostracism [45].

The study underlines the power of digital social networks to share—disseminate—recommend practices across borders of which health professionals may have little awareness. Some patients become precursors, *beta testers*, of solutions never proven or whose manufacturing quality remains to be verified. The study raises important questions about the reliability of CAM information available to patients and regulatory authorities' responsibility for labeling, approval, and surveillance. The results sensitize health professionals and authorities to the power of forums and discussion groups to make known beneficial but also potentially dangerous solutions that currently escape the purview of regulatory and monitoring systems [46]. A recent study shows the risks of CAM in the survival of patients with cancer if they delay the establishment of prescribed cancer treatments or replace them [47]. Other studies indicate that CAM can encourage physicians to listen longer, more thoroughly, and more comprehensively to their patient [8]. More than a nebulous approach, NPIs considered as verified methods become levers of potentiation of biomedical treatments through better patient involvement (eg, adherence and maximization of placebo effect) and supplements acting on most psychosomatic symptoms (eg, nausea, sleep disorders, anxiety and depressive disorders, fatigue, and pain). The study points to a future medical challenge of accurately naming and describing NPIs to promote evidence-based practice and a future that is no longer based on empirical beliefs or advice and to have traceability of uses [48]. This will be even more central, as we see the emergence of integrated supportive care solutions where NPIs are offered as a bouquet of services by a multidisciplinary team [49,50]. Bringing health professionals together through a common vocabulary could reinforce the patient's idea that a close-knit team is doing their utmost to treat their cancer and prevent it from recurring. In the absence of a care path validated/recommended by science and authorities, the uses are mainly based on the preferences, beliefs, and empirical practices, of which a major vector is social networks. There is an urgent need to train doctors who hold NPIs at best for simple general dietary advice and at worst for solutions with no effect on health and cancer, so that they can give clear and up-to-date scientific information to their patients who might be confused by various messages on social media.

### Limitations

Given the confidentiality required for the use of the social network data studied and the ethical framework of this study, it was impossible to know the medical characteristics (eg, type

and severity of cancer, number of recurrences, treatment period, comorbidities, condition health, and risk behaviors) or personal (eg, age), social (eg, social status), and geographical (eg, France vs Francophonie) information on people who wrote a post. Moreover, it was impossible to know if posts were repeated several times by the same person, including on different social networks. Finally, the rules of confidentiality of the networks do not make it possible to affirm with certainty that all published posts emanate from patients with cancer. For example, companies can use these tools by creating virtual patients to promote their nonpharmacological products. Relatives of a sick person can also register to search for information. Impostors could also be spreading false medical information.

Although voluminous and proportional to the attractiveness of CAM, the declarative data did not distinguish interest from real use. Posting can reflect as much a request for information or a doubt as the sharing of actual use of an NPI. Qualitative approaches should complete these mass data analyses to better identify the real choices (eg, medical prescription vs

autoprescription) and context-specific uses. It is essential to know whether these practices are used in a complementary or alternative way to approved and prescribed cancer treatments [46].

Analyses were performed on data compiled between 2006 and 2015. With more data and a longer period of time, it would be interesting to study the chronology of the vocabularies used by patients about NPIs to identify potential *fashion* effects. [51].

## Conclusions

The exploratory study of breast cancer patient forums and Facebook discussion groups raises important questions about the reliability of CAM information available to patients and regulatory authorities' responsibility for labeling, approval, and surveillance. Health professionals and authorities need to be sensitized to the power of forums and discussion groups to make known beneficial but also potentially dangerous solutions that currently escape the purview of regulatory and monitoring systems as mentioned by a recent study.

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## Conflicts of Interest

None declared.

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## Abbreviations

**CAM:** complementary and alternative medicine

**NPI:** nonpharmacological intervention

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Original Paper

# Clinical Profiles and Survival Outcomes of Patients With Well-Differentiated Neuroendocrine Tumors at a Health Network in New South Wales, Australia: Retrospective Study

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## Abstract

**Background:** Neuroendocrine tumors (NETs) are a heterogeneous group of malignancies with varying and often indolent clinicobiological characteristics according to their primary location. NETs can affect any organ and hence present with nonspecific symptoms that can lead to a delay in diagnosis. The incidence of NETs is increasing in Australia; data regarding characteristics of NETs were collected from the cancer registry of Hunter New England, Australia.

**Objective:** This study aimed to explore the clinical profiles and treatment and survival outcomes of patients with well-differentiated NETs in an Australian population.

**Methods:** We reviewed the data of all adult patients who received the diagnosis of NET between 2008 and 2013. The clinicopathological, treatment, and follow-up data were extracted from the local Cancer Clinical Registry. We also recorded the level of remoteness for each patient by matching the patient's residential postcode to the corresponding Australian Bureau of Statistics 2011 remoteness area category. Univariate analysis was used to find the factors associated with NET-related mortality. Survival analysis was computed.

**Results:** Data from 96 patients were included in the study (men: 37/96, 38.5%, and women: 59/96, 61.5%). The median age at diagnosis was approximately 63 years. A higher proportion of patients lived in remote/rural areas (50/96, 52.1%) compared with those living in city/metropolitan regions (46/96, 47.9%). The most common primary tumor site was the gastroenteropancreatic tract, followed by the lung. The factors significantly associated with NET-related mortality were age, primary tumor site, surgical resection status, tumor grade, and clinical stage of the patient. At 5 years, the overall survival rate was found to be 62%, and the disease-free survival rate was 56.5%.

**Conclusions:** Older age, advanced unresectable tumors, evidence of metastasis, and higher-grade tumors were associated with poorer outcomes. Lung tumors had a higher risk of NET-related mortality compared with other sites.

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**KEYWORDS**

Australia; neuroendocrine tumor; New South Wales



## Introduction

### Background

Neuroendocrine tumors (NETs) are a heterogeneous group of malignancies with often indolent clinicobiological characteristics with varying responses to therapy based on the primary tumor location and functional hormonal activity [1]. As these tumors arise from the neuroendocrine cells that are distributed throughout the body, almost any organ can be affected, including the lungs, small intestine, rectum, colon, appendix, and stomach [2,3]. This leads to various nonspecific symptoms and delay in diagnosis. Most NETs are indolent in nature, although some may proliferate rapidly and metastasize to other organs.

NETs were thought to be uncommon, accounting for approximately 2% of all malignant neoplasms; however, the incidence of NET is rising, as shown by different registries available [4,5].

The World Health Organization (WHO) in 2010 proposed a revised classification of NETs based on clinical, pathological, therapeutic, and prognostic factors, with an update released in 2017 [6,7]. Although the incidence of NETs appears to be increasing in Australia [8], the data of the characteristics of NETs among Australian patients are only starting to emerge [9]. Owing to the rarity and difficulty in diagnosis, the clinical, behavioral, and survival outcomes of patients with NETs in this demographic remain ill-defined.

### Objective

This retrospective analysis aimed to determine the incidence, clinical profile, and treatment and survival outcomes of rural and metropolitan patients with well-differentiated NETs in the Hunter New England area, New South Wales, Australia. The Hunter New England Local Health District covers a region of 131,785 square km. It encompasses a major metropolitan center (Newcastle) and regional communities (including Tamworth and Armidale), with a small percentage of people located in remote communities. The estimated resident population is 920,370 people [10].

## Methods

### Patients

Data were collected retrospectively from the local Cancer Clinical Registry, and all patients who received the diagnosis of NET (carcinoid, atypical carcinoid, and well-differentiated NET) between 2008 and 2013 were included. Hematoxylin- and eosin-stained slides that were available at our institution were reviewed for pathological diagnosis and grading according to the 2010 WHO classification and grading system as well as the updated recommendations in the 2017 WHO classification of endocrine organs [6,7]. As for slides that were unavailable for review, data were gathered from laboratory and clinical information systems. Gastroenteropancreatic (GEP) NETs were graded into 3 tiers (G1, G2, and G3) according to the following definitions of mitotic count and Ki-67 index: G1—mitotic count <2 per 10 high-power fields (HPFs) and/or <3% Ki-67 index, G2—mitotic count 2 to 20 per HPF and/or 3% to 20% Ki-67

index, and G3—mitotic count >20 per HPF and/or >20% Ki-67 index. Lung NETs were graded as G1 or typical carcinoid (carcinoid morphology and <2 mitoses/2 mm<sup>2</sup>, lacking necrosis) and G2 or atypical carcinoid (carcinoid morphology and 2-10 mitoses/2 mm<sup>2</sup> or necrosis). Lung NETs with carcinoid morphology but >10 mitoses/2 mm<sup>2</sup> were designated G3. NETs of an unknown primary site were graded based on the grading system of GEP NETs.

The mitotic index is based on the evaluation of mitoses in 50 HPFs (0.2 mm<sup>2</sup> each) in areas of higher density and expressed as mitoses per 10 HPFs (2.0 mm<sup>2</sup>) [7]. The Ki-67 index was calculated using the MIB 1 antibody as a percentage of 500 to 2000 cells counted in areas of strongest nuclear labeling. When the grade differed for mitotic count and Ki-67 index for the same tumor, the higher of the two was taken [7]. Poorly differentiated neuroendocrine carcinomas at any site, and small-cell and large-cell neuroendocrine carcinomas of the lung were excluded because of their vastly different biological and survival profile.

Patient, tumor, treatment, and follow-up details were reviewed according to a predefined standard procedure. Patient characteristics included age at diagnosis, sex, and disease status at last follow-up. We also recorded the level of remoteness for each patient by matching the patient's residential postcode to the corresponding Australian Bureau of Statistics (ABS) 2011 remoteness area (RA) category (2 groups were created: one representing regional Australia, ie, outer regional/inner regional/remote areas, and the other representing metropolitan areas, ie, major cities of Australia [11]). Furthermore, the Socio-Economic Indexes for Areas Index of Relative Socioeconomic Disadvantage (IRSD) was noted as an indicator of patient's level of socioeconomic status [12]. The 2011 IRSD scores and deciles of the index were also recorded from the ABS website. Tumor characteristics included primary location (lung/gastrointestinal tract/pancreas/hepatobiliary system), size (<20 mm vs ≥20 mm), clinical stage (localized and regional vs distant and metastatic), grade, functional activity, and histology. Treatment characteristics included surgical procedures, somatostatin analogue therapy, or chemoradiation.

### Statistical Analysis

All statistical analyses were performed using SAS v9.4 (SAS Institute). The independent variables assessed in this study and included in all subsequent analyses were age, sex, cancer type, remoteness classification category, IRSD decile, tumor category, stage and grade of tumor at diagnosis, and receipt of resection surgery. Status of the patients was extracted from the records based on the last update. The main outcomes assessed in this study were all-cause and NET-related mortality. Furthermore, we also analyzed the 5-year overall survival (OS) and disease-free survival (DFS) rates. Kaplan–Meier analysis was used to estimate the cumulative OS rate. Crude hazard ratios (HRs) were calculated using Cox proportional hazards model to assess the factors associated with all-cause mortality. Competing risk regression model (Fine and Gray hazard model) was applied for assessing the factors associated with mortality because of NETs.

## Results

### Demographic Data

A total of 96 patients with NETs were included in this study (men: 37/96, 38.5%, and women: 59/96, 61.5%; male-to-female ratio, 1.0:1.5; age range, 25-101 years; and median age at

diagnosis, 63 years [interquartile range, 51.5-72.5]). A total of 40 patients (40/96, 41.7%) were aged  $\geq 65$  years. A higher proportion of patients lived in the remote/rural areas (50/96, 52.1%) than in city-metropolitan areas (46/96, 47.9%). The demographic and clinicopathological details of all 96 patients of the study are described in [Table 1](#).

**Table 1.** Characteristics of study participants and their distribution by cause of death.

Characteristic and category	Total (N=96), n (%)	Alive, n (%) <sup>a</sup>	Death due to a neuroendocrine tumor, n (%) <sup>a</sup>	Death due to other causes, n (%) <sup>a</sup>	P value
<b>Age at diagnosis (years)</b>					.001
≤65	56 (58.3)	43 (76.8)	8 (14.3)	5 (8.9)	
>65	40 (41.7)	17 (42.5)	9 (22.5)	14 (35.0)	
<b>Sex</b>					.61
Male	37 (38.5)	21 (56.8)	7 (18.9)	9 (24.3)	
Female	59 (61.5)	39 (66.0)	10 (17.0)	10 (17.0)	
<b>Neuroendocrine tumor site</b>					.002
Lung	30 (31.3)	15 (50.0)	10 (33.3)	5 (16.7)	
Gastroenteropancreatic	55 (57.3)	42 (76.4)	3 (5.5)	10 (18.1)	
Other <sup>b</sup>	11 (11.5)	3 (27.2)	4 (36.4)	4 (36.4)	
<b>Grade at diagnosis<sup>c</sup></b>					.01
1	46 (74.2)	35 (76.1)	2 (4.4)	9 (19.5)	
2-3	16 (25.8)	9 (56.3)	5 (31.2)	2 (12.5)	
<b>Index of relative socioeconomic disadvantage category</b>					.30
<5	54 (56.3)	37 (68.5)	7 (13.0)	10 (18.5)	
≥5	42 (43.8)	23 (54.8)	10 (23.8)	9 (21.4)	
<b>Remoteness category</b>					.22
City	46 (47.9)	25 (54.4)	11 (23.9)	10 (21.7)	
Regional/remote	50 (52.1)	35 (70.0)	6 (12.0)	9 (18.0)	
<b>Resection surgery<sup>c</sup></b>					<.001
No	30 (31.3)	10 (33.3)	13 (43.3)	7 (23.4)	
Yes	65 (67.7)	49 (75.4)	4 (6.2)	12 (18.4)	
<b>Stage at diagnosis<sup>c</sup></b>					.01
Localized	40 (41.7)	32 (80.0)	1 (2.5)	7 (17.5)	
Regional	25 (26.0)	15 (60.0)	5 (20.0)	5 (20.0)	
Distant	30 (31.3)	13 (43.3)	11 (36.7)	6 (20.0)	
<b>Tumor size category<sup>c</sup></b>					.47
<20 mm	33 (47.8)	24 (72.7)	3 (9.1)	6 (18.2)	
≥20 mm	36 (52.2)	23 (63.9)	7 (19.4)	6 (16.7)	

<sup>a</sup>In these columns, the percentage values within parentheses have been calculated row-wise, for example, for the third row,  $(43/56) \times 100 = 76.8$  where N is 56.

<sup>b</sup>Other sites include anterior mediastinum (n=1), ovary (n=1), retroperitoneum (n=1), and unknown primary (n=8).

<sup>c</sup>Information on grade was missing at diagnosis for 34 patients, on resection surgery for 1 patient, on stage at diagnosis for 1 patient, and on tumor size for 27 patients.

Of the total 96 patients, 36 (36/96, 37.5%) died during follow-up (17/96, 18% because of disease and, 19/96, 20% because of other or unknown causes). The number of deaths was greater among men (16/37, 43%) than among women (20/59, 33.9%).

### Clinicopathological Data

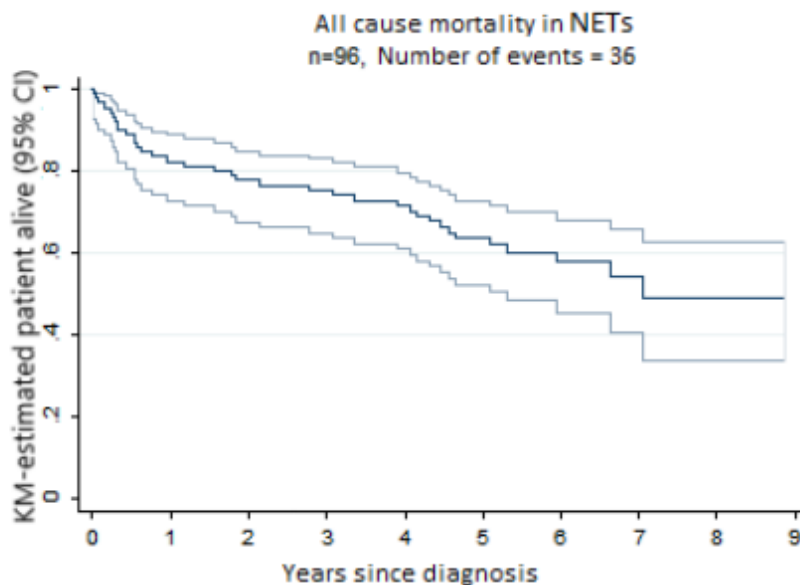
The most common primary site was the GEP tract (55/96, 57.3%), followed by the lung (30/96, 31.3%), and others (11/96, 11.5%). Of the total 96 patients, 35 (35/96, 36.4%) had functional tumors causing carcinoid syndrome. Distant metastases were observed in 30 patients (30/96, 31.3%); 25 patients (25/96, 26%) had regional spread of disease and 40 (40/96, 41.7%) had localized disease. In patients with metastases, metastases to the liver were the most common (27/30, 90%). Overall, 33 patients (33/96, 34.4%) had a tumor size of <20 mm and 36 (36/96, 37.5%) had a tumor size of  $\geq 20$  mm; data of the remaining 27 patients were not available. In

total, 46 patients (46/96, 47.9%) had grade 1, 12 (12/96, 12.5%) had grade 2, 4 (4/96, 4.2%) had grade 3, and 34 (34/96, 35.4%) had an unknown grade.

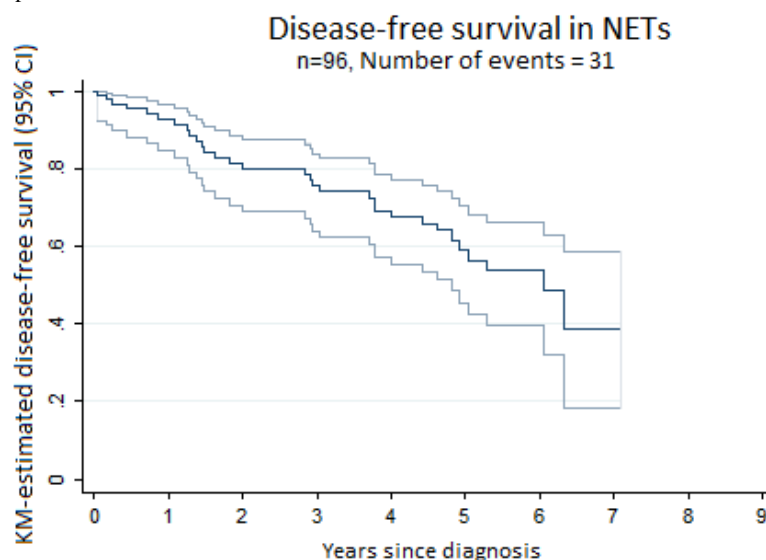
### Survival and Prognostic Factors

Most patients (65/96, 67.7%) underwent resection surgery. The median (interquartile range) follow-up was 4.6 (1.03-5.91) years. The median OS period was 7.04 years and median DFS, 6.04 years. Overall 5-year survival (OS) rate was 62% (Figure 1). The 5-year DFS rate was 56.5% (Figure 2). Figure 3 shows the incidence curve for neuroendocrine cancer-related mortality, having other causes of mortality included as a competing risk.

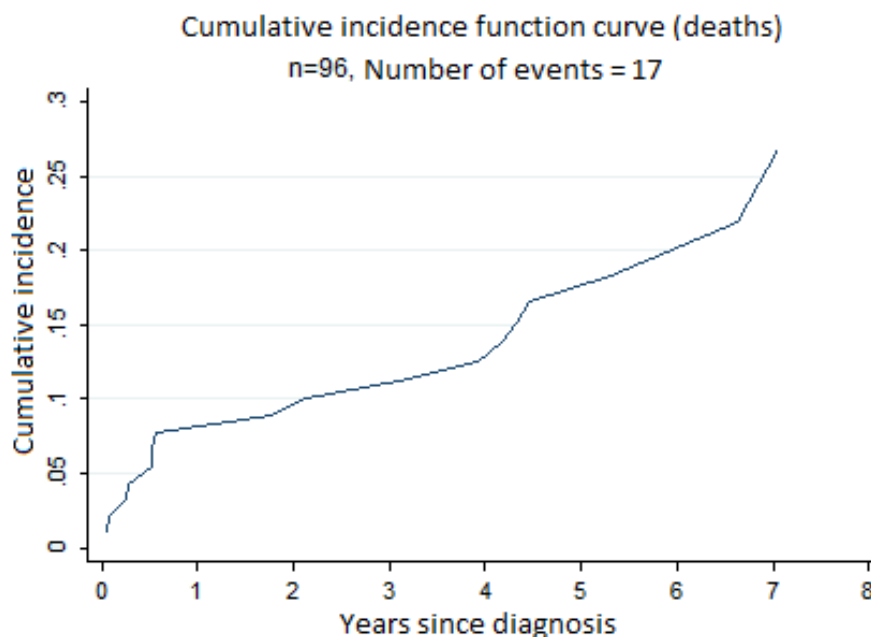
**Figure 1.** Kaplan–Meier (KM) curves for all-cause mortality in patients with neuroendocrine tumors (NETs). Median overall survival (50th percentile) was 7.04 years and 5-year overall survival was 62%.



**Figure 2.** Disease-free survival (DFS) in patients with neuroendocrine tumors (NETs). Median DFS (50th percentile) was 6.04 years and 5-year DFS at 5 years was 56.5%. KM: Kaplan–Meier.



**Figure 3.** Cumulative incidence function curve for neuroendocrine tumors–related mortality, with other causes of mortality included as a competing risk.



### Patient Characteristics Associated With All-Cause Mortality

Table 2 lists all factors significantly associated with all-cause mortality at univariate level.

Older age was found to be significantly associated with an increased risk of mortality (HR 3.05, 95% CI 1.54-6.06;  $P=.001$ ). Men had significantly higher HRs than women, suggesting an increased risk of all-cause mortality among men (HR 4.33, 95% CI 1.52-12.37;  $P=.02$ ). Patients with GEP NETs

had a lower risk of mortality compared with those with NETs of other or unknown sites (HR 0.25, 95% CI 0.10-0.61;  $P=.002$ ). However, there was no difference in the risk of cancer-related mortality between those with GEP NETs and NETs of other or unknown sites. Those who had not received resection surgery had a higher risk of experiencing all-cause mortality than those who had received resection surgery (HR 3.25, 95% CI 1.68-6.30;  $P<.001$ ). Patients with distant metastases had a higher risk of experiencing all-cause mortality than those with a localized or regional tumor (HR 2.15, 95% CI 1.10-4.18;  $P=.02$ ).

**Table 2.** Crude hazard ratios based on Cox proportional hazards model to assess characteristics associated with all-cause mortality in patients with neuroendocrine tumors (N=96).

Characteristic <sup>a</sup> and category	Total deaths (N)	Crude hazard ratio <sup>b</sup> (95% CI)	P value
<b>Age at diagnosis (years)</b>			
≤65	13	Reference	
>65	23	3.05 (1.54-6.06)	.001
<b>Sex</b>			
Male	16	4.33 (1.51-12.37) <sup>c</sup>	.01
Female	20	Reference	
<b>Neuroendocrine tumor site</b>			
Lung	15	0.89 (0.37-2.13)	.80
Gastroenteropancreatic	13	0.25 (0.10-0.61)	.002
Other	8	Reference	
<b>Grade at diagnosis</b>			
1	11	Reference	
2-3	7	1.81 (0.69-4.72)	.23
<b>Remoteness category</b>			
City	21	1.56 (0.80-3.03)	.19
Regional/remote	15	Reference	
<b>Resection surgery</b>			
No	20	3.25 (1.68-6.30)	.001
Yes	16	Reference	
<b>Stage at diagnosis</b>			
Localized/regional	18	Reference	
Distant	17	2.15 (1.10-4.18)	.03
<b>Tumor size category</b>			
<20 mm	9	Reference	
≥20 mm	13	1.43 (0.61-3.36)	.41

<sup>a</sup>Information on grade was missing at diagnosis for 34 patients, on resection surgery for 1 patient, on stage at diagnosis for 1 patient, and on tumor size for 27 patients.

<sup>b</sup>Hazard ratios were based on Cox proportional hazards model.

<sup>c</sup>Hazard ratio adjusted for time interaction.

### Patient Characteristics Associated With Neuroendocrine Tumors–Related Mortality

Table 3 lists all factors significantly associated with NET-related mortality at the univariate level.

Patients with GEP NETs had a lower risk of mortality compared with those with NETs of other or unknown sites (HR 1.41, 95% CI 0.44-4.52;  $P=.01$ ). However, there was no difference in the risk of cancer-related mortality between those with lung NETs and NETs of other or unknown sites. Those who had not

received resection surgery had a higher risk of experiencing all-cause and cancer-related mortality than those who had received resection surgery (HR 35.3, 95% CI 7.75-160.82;  $P=.001$ ). Patients with NETs staged as distant had a higher risk of experiencing NET-related mortality than those with a localized or regional tumor (HR 3.93, 95% CI 1.44-10.68;  $P=.01$ ). Patients diagnosed with a grade 2/3 tumor had a higher risk of experiencing cancer-related mortality than those diagnosed with a grade 1 tumor (HR 6.83, 95% CI 1.38-33.75;  $P=.02$ ).

**Table 3.** Crude hazard ratios based on competing risk regression model to assess characteristics associated with neuroendocrine tumors–related mortality (N=96).

Characteristic and category <sup>a</sup>	Deaths (N)	Crude hazard ratio <sup>b</sup> (95% CI)	P value
<b>Age at diagnosis (years)</b>			
≤65	8	Reference	
>65	9	1.57 (0.62-4.01)	.34
<b>Sex</b>			
Male	7	1.08 (0.41-2.86)	.87
Female	10	Reference	
<b>Neuroendocrine tumor site</b>			
Lung	10	1.41 (0.44-4.55)	.01
Gastroenteropancreatic	3	0.14 (0.03-0.63)	.56
Other	4	Reference	
<b>Grade at diagnosis</b>			
1	2	Reference	
2/3	5	6.83 (1.36-34.21)	.02
<b>Remoteness category</b>			
City	11	1.89 (0.70-5.13)	.21
Regional/remote	6	Reference	
<b>Resection surgery</b>			
No	13	35.31 (7.69-162.2) <sup>c</sup>	.001
Yes	4	Reference	
<b>Stage at diagnosis</b>			
Localized/regional	6	Reference	
Distant	11	3.93 (1.44-10.74)	.01
<b>Tumor size category</b>			
<20 mm	3	Reference	
≥20 mm	7	2.19 (0.57-8.49)	.26

<sup>a</sup>Information on grade was missing at diagnosis for 34 patients, on resection surgery for 1 patient, on stage at diagnosis for 1 patient, and on tumor size for 27 patients.

<sup>b</sup>Hazard ratio was based on the competing risk regression model (Fine and Gray hazard model), and “death due to other causes” was considered a competing risk.

<sup>c</sup>Hazard ratio adjusted for time interaction.

## Discussion

### Principal Findings

NETs originate from neuroendocrine cells, with the most common sites being the small bowel, rectum, appendix, colon, stomach, and lungs. Nevertheless, NETs can arise in almost any organ. In this retrospective study, we collected and analyzed the incidence, clinical profiles, and treatment outcomes of 96 patients with low-grade NETs over a 5-year duration. The patient characteristics significantly associated with death due to NETs were older age, tumor type, stage at diagnosis, and grade at diagnosis.

### Limitations

Our study had a few limitations. Multivariate analyses were precluded by the limited patient population; hence, we have only presented unadjusted analyses of our findings. Therefore, evaluation in a larger population of such tumors is warranted.

### Comparison With Previous Studies

The gastrointestinal tract is believed to be the most frequent location of NETs—confirmed by our data of an Australian population—followed by the lung and others. Our results confirm and corroborate findings reported in the epidemiological study by Luke et al [9]. However, another recent study involving advanced NETs has demonstrated the small intestine to be the most common site, closely followed by the lung [13]. An analysis of our study results revealed that the primary site of

the tumor is a major factor associated with mortality, as patients with GEP NETs had a significantly lower risk compared with those with lung NETs, extraintestinal NETs, and NETs of an unknown primary site.

The median age of patients at diagnosis in our study was approximately 63 years. This finding is similar to that reported in a study in the United States where the median age at diagnosis was 63 years [4]. Our results show that older age is significantly associated with an increased risk of both all-cause and NET-related mortality. This is in line with the findings of the study by Strosberg and Cheema [14], who had evaluated the data of 425 patients with pancreatic NETs.

Previous data have shown that survival in patients with NETs varies according to the tumor grade, and hence it is an important factor to predict survival. The American Joint Committee on Cancer reported an HR of 2.3 in intermediate-grade tumors versus low-grade tumors and of 5.4 in high-grade tumors versus low-grade tumors [14]. Our results found that patients with grade 2/3 tumors had a higher risk of experiencing cancer-related mortality than those with a grade 1 tumor.

In accordance with other studies in different geographic regions, metastatic disease at diagnosis and higher grade of tumors were associated with mortality. The rate of distant metastases in our series (31.3%) was slightly higher compared with that reported by Taal and Visser in their study (12%-25%) [15]. This could

be explained by the higher proportion of patients living in remote/rural areas in our study population, which could be attributed to poorer access to advanced health care services. This finding is in line with that from a previous study [14]. In addition, tumors of unknown primary (n=8) were included in this study, which might have resulted in a bias toward a higher rate of distant metastases in our series.

Nearly one-third of the Australian population live in regional and remote areas, and the proportion of cancer-related deaths is observed to be higher in this demographic [16]. For both sexes, the age-standardized mortality rates of the regional and rural areas have shown no evidence of improvement as opposed to that among the urban residents [17]. This is plausibly related to the access to specialized cancer care in addition to other factors such as higher prevalence of cancer risk factors, such as smoking and sun exposure, and higher prevalence of other comorbidities.

## Conclusions

In our cohort of patients with NETs from rural and metropolitan regions of Australia, we have shown that older age, extraintestinal NETs, unresectable tumors, evidence of metastasis, and higher-grade tumors contributed to significantly poorer outcomes. Furthermore, patients from rural/remote areas have inferior clinical outcomes compared with those from city/metropolitan areas.

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## Conflicts of Interest

None declared.

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## Abbreviations

**ABS:** Australian Bureau of Statistics  
**DFS:** disease-free survival  
**GEP:** gastroenteropancreatic  
**HPF:** high-power field  
**HR:** hazard ratio  
**IRSD:** index of relative socioeconomic disadvantage  
**NET:** neuroendocrine tumor  
**OS:** overall survival  
**WHO:** World Health Organization

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Original Paper

# A Technology-Assisted, Brief Mind-Body Intervention to Improve the Waiting Room Experience for Chemotherapy Patients: Randomized Quality Improvement Study

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## Abstract

**Background:** Patients waiting for chemotherapy can experience stress, anxiety, nausea, and pain. Acupressure and meditation have been shown to control such symptoms.

**Objective:** This study aimed to evaluate the feasibility and effectiveness of an integrative medicine app to educate patients about these self-care tools in chemotherapy waiting rooms.

**Methods:** We screened and enrolled cancer patients in chemotherapy waiting rooms at two Memorial Sloan Kettering Cancer Center locations. Patients were randomly assigned into an intervention arm in which subjects watched acupressure and meditation instructional videos or a control arm in which they watched a time- and attention-matched integrative oncology lecture video. Before and after watching the videos, we asked the patients to rate four key symptoms: stress, anxiety, nausea, and pain. We performed the analysis of covariance to detect differences between the two arms postintervention while controlling for baseline symptoms.

**Results:** A total of 223 patients were enrolled in the study: 113 patients were enrolled in the intervention arm and 110 patients were enrolled in the control arm. In both groups, patients showed significant reductions in stress and anxiety from baseline (all  $P < .05$ ), with the treatment arm reporting greater stress and anxiety reduction than the control arm (1.64 vs 1.15 in stress reduction;  $P = .01$  and 1.39 vs 0.78 in anxiety reduction;  $P = .002$ ). The majority of patients reported that the videos helped them pass time and that they would watch the videos again.

**Conclusions:** An integrative medicine self-care app in the waiting room improved patients' experiences and reduced anxiety and stress. Future research could focus on expanding this platform to other settings to improve patients' overall treatment experiences.

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**KEYWORDS**

mobile app; acupressure; meditation; symptom relief; chemotherapy

## Introduction

Ambulatory parenteral chemotherapy is a common mainstream cancer treatment. Long wait times for chemotherapy can cause

patient dissatisfaction and anticipatory nausea [1,2]. At the time of this study, a commonly cited complaint among patients was a long waiting time from check-in to receiving chemotherapy at the Memorial Sloan Kettering Cancer Center's (MSK)

Rockefeller Outpatient Pavilion and Breast and Imaging Center. Long delays in chemotherapy waiting rooms can trigger patients to feel stress, anxiety, pain, and anticipatory nausea. These symptoms can cause adverse treatment experiences and incur health care cost if intervention is needed.

Integrative therapies such as acupressure and mindfulness meditation are used by individuals undergoing cancer treatments to alleviate symptoms such as pain, nausea, and anxiety. Acupressure is a therapy achieved by pressing along acupoints, which are histologically distinct cutaneous areas with high electrical conductivity, throughout the body [3]. Stimulating these acupoints releases endorphins and various neurotransmitters, such as serotonin and norepinephrine, which consequently provide symptomatic relief [4-6]. Acupressure provides a nonpharmacological, noninvasive approach for patients to effectively manage emotional and physical conditioned responses they experience in the waiting room [7]. The efficacy of acupressure in reducing chemotherapy-induced nausea and vomiting has been suggested through numerous clinical trials and systematic reviews [8-10]. Among them, the subgroup analysis of a meta-analysis of 11 randomized controlled trials (N=1247) on acupuncture point stimulation showed that acupressure significantly reduced mean acute chemo-induced nausea severity and most severe acute nausea [8,9]. Similarly, mindfulness meditation has been extensively studied and shown to reduce anxiety and stress [11-14]. It is a mind-body technique that places intentional focus on the present state of the body to achieve relaxation. Both acupressure and mindfulness meditation are accessible, low-cost therapeutic modalities that can be self-administered by patients with no adverse side effects.

Although useful, these integrative modalities are not readily available in the outpatient setting. Written instructions on acupressure are available in MSK's Web-based patient and caregiver education library, but patients are either not aware of or do not have access to them. Podcasts on guided imagery and relaxation techniques are also available on MSK's website but are rarely used because of inconvenience. Previous integrative medicine classes adjacent to chemotherapy waiting rooms had low attendance rates as patients were fearful of missing their appointments.

A potential solution to effectively deliver therapeutic modalities directly to patients is through technological apps. Technological apps have become increasingly prevalent in the health care setting because of their ease of accessibility and enhancement of patient care through personalization. Today, technological apps are used to monitor and manage symptoms in patients with diabetes, cancer, inflammatory bowel disease, depression, and anxiety [15]. Through these apps, patients can access medical guidance more easily and also develop an increased sense of agency over their symptoms.

Researchers have also studied the use of apps to manage and monitor symptoms as well as to improve medication adherence in patients with chronic conditions [16]. Studies have also examined the effectiveness of psycho-educational apps in providing self-guided mental health interventions for patients outside the clinical setting [17], and studies have investigated

how to efficiently use apps in obstetrics and gynecology waiting rooms to educate patients on topics such as contraception [18]. However, to our knowledge, this is the first study to examine the effects of using an app to deliver integrative therapies and education to alleviate adverse symptoms induced by long wait times in chemotherapy waiting rooms. As such, we conducted a quality improvement (QI) study to evaluate the feasibility and effects of introducing an integrative medicine app at MSK, delivering self-administered therapeutic techniques to improve the overall treatment experience. A QI study allows us to directly assess whether a new process, such as this one, provides direct benefit to patient outcomes and overall quality of care.

## Methods

### Participants

We obtained an MSK Institutional Review Board waiver as the study represented minimal risk, and we did not collect any personal health information. Patients scheduled to receive chemotherapy at 2 locations at MSK (Rockefeller Outpatient Pavilion and Breast and Imaging Center) were consecutively screened as they checked in for their appointments. Patients who were receiving chemotherapy for the first time and non-English speaking patients were excluded.

Without previous knowledge of the assignment, an MSK staff member would approach patients with a sealed envelope containing assignment group A or B. Patients were asked if they would like to watch a video and participate in a survey. Once patients agreed, a staff member would then open the sealed envelope to reveal the patient's assigned group (video A or B). Study staff then selected the appropriate video and briefed patients on how to use the app on a tablet in the waiting room. Patients proceeded to watch either the intervention or control video (both 15 min long).

### App

All integrative medicine education videos and surveys were run through a third-party health care app, Tonic Health. MSK Compliance and Information Security conducted a controls security assessment and hands-on penetration test to confirm Tonic Health as a secure app that complied with the MSK Security policy.

### Intervention and Control

Patients randomized to the intervention arm watched videos instructing them to perform acupressure at 3 acupoints known to reduce anxiety, stress, and nausea: pericardium-6 (located 3 finger-breadths below the wrist on the inner forearm in between the 2 tendons), Yin Tang (located midway between the medial ends of 2 eyebrows), and stomach-36 (located 4 finger-widths down 1 finger lateral from the bottom of the knee cap). In addition to the acupressure session, intervention patients also viewed a guided meditation video that included a series of breathing and visualization exercises accompanied by gentle music. The script was developed by an MSK mind-body therapist, MSK clinical staff recorded all content, and the MSK Video and Conference Services department edited the content. Patients randomized to the control arm were instructed to watch

a 15-min lecture by an integrative medicine physician introducing integrative medicine modalities for cancer patients.

## Outcomes

All patients were asked 4 questions to rate the levels of nausea, stress, headaches/generalized pain, and anxiety they were experiencing at the start and end of the video. They assessed the degree of each of their symptoms using a 0-10 Likert numerical rating scale (with 0 indicating no symptoms and 10 indicating worst symptoms imaginable). This scale has been used previously in clinical trials to effectively assess symptoms such as pain, stress, and anxiety [19-23]. At the end of the session, patients provided qualitative feedback on the study by rating their satisfaction through the following 3 questions: (1) Did you find the videos helpful?, (2) Did the videos help you pass time?, and (3) Are you interested in watching MSK self-care videos in the future? These questions were then followed by an open-field comments section for patients to provide testimonials regarding their experiences.

## Statistical Analysis

The means and standard deviations for symptom scores were calculated in both the intervention and control arms. Paired *t* tests were used to evaluate changes in symptom score before and after watching the videos in each treatment arm. The difference in symptom scores between treatments was assessed with an analysis of covariance model, with the postvideo symptom score as the outcome and the treatment group and baseline symptom score as covariates. All analyses were performed using Stata 12 (StataCorp).

## Results

### Participants

From October 19, 2016, to December 29, 2016, we approached 363 patients when they arrived at 2 chemotherapy waiting rooms

**Table 1.** Symptoms changes in both the intervention and control groups.

Symptoms	Intervention group, mean (SD)		Control group, mean (SD)		Between group <i>P</i> value
	Pre	Post	Pre	Post	
Stress	3.5 (2.5)	1.9 (2.0)	3.6 (2.6)	2.5 (2.3)	.01 <sup>a</sup>
Pain	1.8 (2.1)	1.5 (1.9)	1.7 (2.2)	1.5 (2.2)	.55
Nausea	0.9 (1.9)	0.8 (1.9)	0.9 (1.9)	0.7 (1.4)	.32
Anxiety	3.2 (2.7)	1.7 (2.2)	3.1 (2.7)	2.2 (2.2)	.002 <sup>a</sup>

<sup>a</sup>Statistically significant value: <.05.

### Patient Experience

We surveyed patients in both the intervention and control groups regarding their experiences using these videos (Table 2).

In the intervention group, 95/103 (92.2%) of the patients reported to have found the videos helpful, 96/103 (93.2%) of the patients found that the videos helped them pass time while waiting for their appointment, and 78/103 (75.7%) of the patients were interested in watching MSK self-care videos in the future. In the control group, 88/102 (86.2%) of the patients found the

at MSK. Among these, 61.4% (223/363) agreed to participate in the study, and they were subsequently randomized into the intervention arm (n=113) or the control arm (n=110). Within the intervention arm, 103 out of 113 patients (91.1%) completed the intervention video and survey. Within the control arm, 102 out of 110 patients (92.7%) completed the education video and survey. Of the 363 patients approached, 140 patients declined to participate in the study, as they were either called in for their appointment or chose to engage in other activities during the waiting period. Of the 223 participants, 9 patients in the intervention arm were called into their appointment before completing the video, and 1 patient stated that the video made her more anxious. In the control group, 7 patients were called into their appointment before completing the video, and 1 patient opted to spend time with family instead. There were no significant differences in baseline measures between dropouts and patients who completed the study.

### Symptoms

Baseline symptoms were similar between the intervention and control arms. After watching the intervention self-care videos, patients' stress, pain, and anxiety were significantly reduced compared with baseline (stress from 3.6 to 1.9, pain from 1.8 to 1.5, and anxiety from 3.1 to 1.7; all *P*<.05), without significant changes in nausea (2A). After watching the control video, patients' stress and anxiety were also significantly reduced (stress from 3.6 to 2.5 and anxiety from 3.0 to 2.2; both *P*<.001), without significant changes in nausea and pain. Compared with the control arm, the intervention arm showed a significantly greater reduction in stress and anxiety (1.64 vs 1.15 in stress reduction; *P*=.01 and 1.39 vs 0.78 in anxiety reduction; *P*=.002 (Table 1).

videos helpful, 92/102 (90.1%) of the patients agreed that the videos helped them pass time, and 80/102 (78.4%) of the patients wanted to watch MSK self-care videos in the future. No adverse events were reported in either group throughout the sessions. Patients' testimonials regarding videos were positive. One patient stated:

*I never realized that a person could find pressure points on their body to help relieve issues like nausea and GI discomfort. These videos were very informative!*

**Table 2.** Patient-rated experiences.

Survey questions	Intervention group		Control group	
	Yes, n (%)	No, n (%)	Yes, n (%)	No, n (%)
Were these videos helpful to you?	95 (92)	8 (8)	88 (86)	14 (14)
Did these videos help you pass time during your visit today?	96 (93)	7 (7)	92 (90)	10 (10)
In the future, would you like the option to watch the Memorial Sloan Kettering Cancer Center's videos while waiting for your appointments?	78 (76)	25 (24)	80 (78)	24 (22)

Similarly, another patient reported that the video “helps to pass time while waiting for treatment. Helpful tips to decrease anxiety and stress.” Interest in viewing more interventional videos in the future was also expressed:

*Very helpful, I would like it if there were links to video showing some of the meditation or yoga techniques.*

## Discussion

### Principal Findings

Prolonged wait times in chemotherapy waiting rooms account for many of the negative experiences associated with cancer treatments. Anticipating the awaited treatment can induce debilitating symptoms such as anxiety and stress. Although prior research and QI efforts have focused on shortening treatment wait times, limited investigation has been done on how to enhance overall patient experiences in chemotherapy waiting rooms. This study showed that we could utilize an integrative medicine app effectively and safely to improve patients' waiting room experience.

In this study, we demonstrated that the use of an integrative medicine app to deliver guided acupressure and mindfulness meditation is feasible and beneficial in chemotherapy waiting rooms. We found a significantly higher reduction in stress and anxiety levels in the group exposed to the acupressure and meditation video when compared with the control group. In addition, we found a significant reduction in pain compared with baseline in the intervention group, whereas there was no significant change in pain in the control group. Although this study showed that our intervention videos did not improve nausea, this may be because of the fact that our participants demonstrated a very low median baseline nausea score (0.8 out of 10) to start with, leaving little room for improvement.

The efficacy of acupressure in relieving chemotherapy-induced stress and anxiety, as shown in this study, is consistent with findings in previous studies, which showed that different forms of acupressure significantly reduced pretreatment anxiety and chemotherapy-induced nausea [24,25]. A previous QI study found that providing patients with guided meditation delivered through iPads decreased average distress levels by 46% ( $P < .01$ ) in patients undergoing chemotherapy [26]. Another clinical trial also found that mindfulness interventions significantly lowered blood pressure, heart rate, oxygen saturation, and perceived stress in women undergoing breast biopsies [27]. A recent study in 108 cancer patients also showed that a single-session mindfulness practice significantly reduced anxiety levels and lowered heart rates in patients undergoing positron emission tomography-computed tomography scans [28].

However, this is the first study to utilize an app to educate patients on using acupressure and mindfulness meditation to achieve the same outcomes of significantly reducing patient anxiety and stress. Our results further demonstrated the effectiveness and feasibility of extending this therapy to chemotherapy waiting rooms to enhance patient experiences while awaiting treatment. In addition, the overall feedback we received from participants about their experiences was very positive, with a majority of them expressing that the videos were helpful, helped them pass time, and that they wanted further access to such videos.

Although we were not surprised that the intervention group demonstrated a significant reduction in stress and anxiety, it is interesting to note that the control group also demonstrated a reduction in stress and anxiety levels, suggesting that symptomatic relief may also be accomplished by certain distractions. This finding suggests that the integrative medicine app can serve as a platform to educate patients about available integrative cancer therapies and also aid in alleviating symptoms. It is important to note that our intervention videos resulted in greater symptomatic relief, indicative of effects extending beyond distraction alone. Overall, this study demonstrates that an integrative medicine app could be an invaluable tool for enhancing the overall chemotherapy waiting room experience. As adverse symptoms are often responsible for poor chemotherapy tolerance, the efficacy of these technological apps in alleviating symptoms through delivering self-care techniques can potentially improve treatment tolerance.

There are a few limitations to this study. It was a single-center study, and we excluded non-English speaking patients. In addition, patients could have more relief from their symptoms if they watched the video more than once. This study is further limited by the exclusion of patients who were scheduled to have their first chemotherapy session. As these patients are often already overwhelmed, we assumed that their baseline symptoms would be heightened and the effectiveness of the intervention would not be accurately assessed. Finally, our assessment focused on the immediate effect of the intervention on symptoms. We do not have any information on the effect of our intervention, if any, in the long term (ie, if patients implemented the techniques they learned through the app at subsequent time points and what the effect of these may have been).

To the best of our knowledge, this is the first study to explore the use of self-care apps to improve patients' waiting room experiences. Previous studies have investigated the use of mobile apps in patient care coordination and clinical practices but not in the chemotherapy waiting room [29,30].

This study showed the feasibility and effectiveness of an integrative medicine app in waiting rooms and provided the foundation for future exploration of expanding the use of technological interventions in this setting. To improve the integrative medicine app experience, we could provide devices available at check-in, make the app accessible on personal devices, and provide direct links to self-care videos as well as the MSK integrative medicine Web page for additional resources. Future research could focus on expanding this

platform in other waiting room settings to improve overall patient treatment experiences.

## Conclusions

Providing self-care tools through an integrative medicine app in the waiting room improved patients' experiences and reduced overall anticipation-induced anxiety and stress levels. Future research could focus on expanding this platform to other settings to improve patient treatment experiences and increase awareness of integrative medicine.

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## Conflicts of Interest

None declared.

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## Abbreviations

**MSK:** Memorial Sloan Kettering Cancer Center

**QI:** quality improvement

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